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OXFORD TEXTBOOKS IN PALLIATIVE MEDICINE

Oxford Textbook of Palliative Nursing

FIFTH EDITION

EDITED BY
Betty Rolling Ferrell
Judith A. Paice

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Oxford Textbook of
Palliative Nursing

Advance Praise for *Oxford Textbook of Palliative Nursing, Fifth Edition*

"This is the ultimate go-to book for nurses caring for patients at end of life and a must for all libraries. The textbook is fresh, current, and clinician friendly. For nurses caring for children and their families, three new chapters in this edition offer critical new information on caring for adolescents, using social media to communicate, and accessing pediatric care. Congratulations to the editors for producing such a comprehensive resource for all nurses, including pediatric nurses."

—**Lisa C. Lindley, PhD, RN, FPCN**, Associate Professor, College of Nursing, University of Tennessee, Knoxville, TN

"What I immediately liked about this new edition of the *Oxford Textbook of Palliative Nursing* are the chapters from new authors that both encompass a multidisciplinary approach and address today's healthcare, including such topics as value-based care, advance care planning, and organ donation. The last chapter in particular, "The Ethos of Palliative Nursing," summarizes the essence of palliative care to guide nurses on focusing on the quality of life and support of patients and their family members."

—**Rose Virani, RNC, MHA, OCN, FPCN**, Senior Research Specialist and ELNEC Project Director,
Division of Nursing Research and Education, City of Hope, Duarte, CA

"Since its inception, the *Oxford Textbook of Palliative Nursing* has been the go-to resource for nurses and nurse practitioners caring for seriously ill patients and their families. The new Fifth Edition continues in that venerable tradition as an excellent resource for nurses at the bedside, in the classroom, and conducting research in the field of palliative care. This edition reflects the growth of the field of palliative care nursing, both in breadth as palliative care expands to new settings and populations as well as depth as the evidence base for palliative care continues to mature. Congratulations to the editors and authors for producing such an outstanding textbook."

—**Sally Norton, PhD, RN, FNAP, FPCN, FAAN**, Associate Professor and Independence
Foundation Chair in Nursing and Palliative Care, University of
Rochester School of Nursing, Rochester, NY

"The comprehensive scope and content of the *Oxford Text of Palliative Nursing, Fifth Edition,* is a testament to the growth in the specialty of palliative nursing. This book will serve as an essential resource for hospice and palliative nurses and other members of the interdisciplinary team, as well as for clinicians who practice in other clinical specialties, but provide care for seriously ill patients and their families. The last chapter, "The Ethos of Palliative Nursing," provides a great review of the moral nature of palliative nursing and provides a wonderful framework for self-reflection."

—**Sally Welsh, MSN, RN, NEA-BC**, Chief Executive Officer, Hospice and Palliative Nurses Association,
Hospice and Palliative Credentialing Center, Hospice and Palliative Nurses Foundation, Savannah, GA

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Dedication

This fifth edition of the Oxford Textbook of Palliative Nursing is dedicated to Nessa Coyle PhD, RN, co-editor of each of the previous four editions of this textbook. While Nessa is not an editor for this book, her career contributions are evident in every chapter and her wisdom is well reflected in her chapter in this edition, "Advocacy in Palliative Nursing."

A textbook such as this is only possible once a field has evolved to the point of having both scholarly work and clinical experience to share. Nessa has been a pioneer in both of these worlds, a true clinician scholar who has lived the work of palliative nursing at the bedside while also contributing some of the most insightful scholarship that defines palliative nursing.

This year (2018) marks Nessa's 60th year as a nurse. Her pioneering work in cancer pain management helped advance not only the pharmacologic approaches to care, but also the palliative care rendered by the nurses at the bedside to ease the profound suffering of people living and dying in pain. Nessa was one of the first nurses to teach us about the existential aspects of palliative nursing and our role in supporting patients and families through grief, spiritual distress, and a search for meaning during serious illness. Her qualitative research provided insight for generations of nurses and other professionals as she shared the worlds of the real experts—patients—and the lessons they teach us about this field we know as palliative care.

We dedicate this 5th edition to Nessa. Every section and every chapter within it are a testament to her influence on nursing. Through her gentle yet profoundly strong voice, we have been guided to deliver the care described in these pages.

Betty Ferrell
Judy Paice

Contents

Preface *xiii*

Acknowledgments *xv*

Contributors *xvii*

SECTION I
General Principles

1. **Introduction to Palliative Care** *3*
Betty Rolling Ferrell

2. **National Consensus Project for Quality Palliative Care: Assuring Quality Palliative Care through *Clinical Practice Guidelines*** *5*
Constance M. Dahlin

3. **Hospital-Based Palliative Care** *13*
Patricia Maani-Fogelman

4. **Principles of Patient and Family Assessment** *32*
John D. Chovan

5. **Communication in Palliative Care: An Essential Competency for Nurses** *55*
Constance M. Dahlin and Elaine Wittenberg

6. **Advance Care Planning** *79*
Shigeko Izumi

SECTION II
Symptom Assessment and Management

7. **Interdisciplinary Palliative Care Teams: Specialists in Delivering Palliative Care** *89*
Polly Mazanec, Rebekah Reimer, Jessica Bullington,
Patrick J. Coyne, Herman Harris, II,
Mary Catherine Dubois, Catherine Rogers,
and Jennifer Aron

8. **Pain Assessment** *98*
Regina M. Fink, Rose A. Gates, and Kate D. Jeffers

9. **Pain Management** *116*
Judith A. Paice

10. **Fatigue** *132*
Edith O'Neil-Page, Grace E. Dean, and Paula R. Anderson

11. **Anorexia and Cachexia** *140*
Elizabeth E. Schack and Dorothy Wholihan

12. **Nausea and Vomiting** *149*
David Collett and Kimberly Chow

13. **Dysphagia, Hiccups, and Other Oral Symptoms** *163*
Rachel Klinedinst, Audrey Kurash Cohen,
and Constance M. Dahlin

14. **Bowel Management: Constipation, Obstruction, Diarrhea, and Ascites** *186*
Stefanie N. Mooney, Purvi Patel, and Sorin Buga

15. **Medically Administered Nutrition and Hydration** *206*
Katy M. Lanz, Michelle S. Gabriel, and Jennifer A. Tschanz

16. **Dyspnea, Cough, and Terminal Secretions** *217*
DorAnne Donesky

17. **Bladder Management in Palliative Care** *230*
Naomi Farrington and Catherine Murphy

18. **Lymphedema Management** *238*
Mei R. Fu, Bonnie B. Lasinski, Janet H. Van
Cleave, and Charles P. Tilley

19. **Palliative Wound, Ostomy, and Continence Care** *251*
Charles P. Tilley, Mei R. Fu, and Jana M. Lipson

20. **Pruritus, Fever, and Sweats** *285*
Angel Smothers

21. **Neurological Disorders** *291*
Margaret A. Schwartz

22. **Anxiety and Depression** *309*
Jaroslava Salman, Emma Wolfe, and Sunita K. Patel

23. **Delirium, Confusion, and Agitation** *319*
Wendy Goldberg, Greg Mahr, Amy M. Williams, and Michael Ryan

24. **Insomnia** *330*
Karla Schroeder

25. **Sexuality and Intimacy in Serious Illness and at the End of Life** *337*
Heather Shaw and Joshua Fronk

26. **Urgent Syndromes at the End of Life** *344*
Quinten Robertson and Kelli Gershon

27. **Sedation for Refractory Symptoms** *356*
Chandana Banerjee and Bonnie Freeman

28. **Complementary and Integrative Therapies in Palliative Care** *361*
Mary-Anne Meyer and Melinda Ring

29. **Withdrawal of Invasive Mechanical Ventilation** *371*
Margaret K. Campbell

SECTION III

Psychosocial and Spiritual Support

30. **The Meaning of Hope in the Dying** *379*
Valerie T. Cotter and Anessa M. Foxwell

31. **Bereavement** *390*
Inge B. Corless and Janice Bell Meisenhelder

32. **Supporting Families and Family Caregivers in Palliative Care** *405*
Kelli I. Stajduhar and J. Nicholas Dionne-Odom

33. **Planning for the Actual Death** *420*
Patricia Berry and Julie Griffie

34. **Spiritual Screening, History, and Assessment** *432*
Elizabeth Johnston Taylor

35. **Spiritual Care Intervention** *447*
William Rosa

36. **Meaning in Illness** *456*
Tami Borneman and Katherine Brown-Saltzman

SECTION IV

Special Patient Populations

37. **Cultural Considerations in Palliative Care** *469*
Carrie Cormack, Polly Mazanec, and Joan T. Panke

38. **Older Adult Patients in the Community** *483*
Carol O. Long

39. **Poor, Homeless and Underserved Populations** *490*
Caroline Olney, Sarah Stroe, and Anne Hughes

40. **Palliative Care for Patients with Mental Illness** *503*
John D. Chovan and Betty D. Morgan

41. **Palliative Care for People Living with HIV** *513*
Jacquelyn Slomka

42. **Caring for the Patient with Substance Use Disorder at the End of Life** *521*
Peggy Compton, Yu-Ping Chang, and Salimah Meghani

43. **Cancer Survivorship** *530*
Anne Reb and Denice Economou

44. **Veterans** *539*
Deborah Grassman

45. **Organ Donation** *545*
Lissi Hansen and Lauren F. Dunn

46. **Pulmonary Palliative Care** *552*
Patricia A. Maani-Fogelman and Ruby A. Weller

47. **Palliative Care in Heart Failure** *559*
J. Nicholas Dionne-Odom, Rachel Wells, and Keith M. Swetz

SECTION V

End-of-Life Care across Settings

48. **Improving the Quality of Care across All Settings** *573*
Marilyn Bookbinder, Romina Arceo, and James T. McDaniel

49. **Long-Term Care: Focus on Nursing Homes** *606*
Joan Carpenter and Mary Ersek

50. **Palliative Care in the Community** *615*
Nancy Robertson and Barbara Sutton

51. **The Intensive Care Unit** *624*
Jennifer K. McAdam and Céline Gélinas

52. **Palliative Care Nursing in the Outpatient Setting** *639*
Pamela Stitzlein Davies and Kathleen Broglio

53. **Palliative Care in the Emergency Department** *652*
Rebecca Wright and Benjamin Roberts

54. **The Role of Nursing in Caring for Patients Receiving Palliative Surgery or Chemotherapy** *660*
Virginia Sun, Tami Tittelfitz, and Marjorie J. Hein

55. **Rural Palliative Care** *670*
Richard A. Taylor, J. Nicholas Dionne-Odom, Erin R. Currie, Macy Stockdill, and Marie A. Bakitas

56. **The Role of PT, OT, and Other Therapies in Palliative Care for Seriously Ill Patients** *682*
Dennis Lin, Megan Borjan, Seanell D. San Andres, and Christina Kelly

57. **Value-Based Care** *690*
Finly Zachariah and William Dale

SECTION VI

Pediatric Palliative Care

58. **Symptom Management in Pediatric Palliative Care** *699*
Joan "Jody" Chrastek and Camara van Breemen

59. **Pediatric Hospice and Palliative Care** *708*
Vanessa Battista and Gwenn LaRagione

60. **Pediatric Goals of Care: Leading through Uncertainty** *727*
Christina McDaniel and Jordan M. Desai

61. **End-of-Life Decision-Making in Pediatric Oncology** *736*
Deborah A. Lafond and Katherine Patterson Kelly

62. **Palliative Care in the Perinatal Setting: Neonatal Intensive Care Unit, Labor and Delivery Unit** *749*
Cheryl Ann Thaxton, Diana Jacobson, Heather Murphy, and Tracey Whitley

63. **Grief and Bereavement in Perinatal and Pediatric Palliative Care** *758*
Rana Limbo, Kathie Kobler, and Betty Davies

64. **Pediatric Pain: Knowing the Child Before You** *773*
Juliana H. O'Brien and Maggie C. Root

65. **Supporting Adolescents with a Parent in Hospice** *783*
Denice Sheehan, Pamela Stephenson, M. Murray Mayo, Diane Snyder Cowan, and Dana Hansen

66. **Use of Social Media as a Communication Tool for People with Serious Illness and Their Families** *791*
Dana Hansen, Amy Petrinec, and Nidal Harb

67. **Access to Pediatric Hospice and Palliative Care** *800*
Lisa C. Lindley and Jessica Keim-Malpass

SECTION VII

Special Issues for the Nurse in End-of-Life Care

68. **The Advanced Practice Registered Nurse** *809*
Clareen Wiencek and Alexander Wolf

69. **Self-Care** *817*
Kathy G. Kravits

70. **Ethical Considerations in Palliative Care** *824*
Maryjo Prince-Paul and Barbara J. Daly

71. **Palliative Care and Requests for Assistance in Dying** *837*
Carey T. Ramirez, Kathleen Fundalinski, Judy Knudson, and John Himberger

72. **Nursing Education** *844*
Pam Malloy and Andra Davis

73. **Nursing Research** *855*
Terrah Foster Akard, Karen Hyden, and Mary Jo Gilmer

74. **Advocacy in Palliative Nursing: A Conceptual Model** *861*
Nessa Coyle and Timothy W. Kirk

75. **Global Palliative Care** *868*
Virginia LeBaron and Annette Galassi

76. **The Ethos of Palliative Nursing** *877*
Mark Lazenby and Michael Anthony Moore

Index *881*

Preface

The first edition of this Textbook was published in 2001 with the primary intent of helping to define the field of Palliative Nursing as a very new specialty. There has been enormous progress over these years, far exceeding even our own expectations, and each of the subsequent editions of the book has reflected the progress of the field and the contributions of nursing as members of interdisciplinary teams dedicated to competent and compassionate care of the seriously ill.

This fifth edition of the Oxford Textbook of Palliative Nursing moves the field a very big step forward as our field is now recognized as a critical nursing specialty in healthcare but also vastly growing in demand as essential to primary care practice in all settings of nursing. From the neonatal ICU to the long-term care setting for elders, palliative care provides attention to the physical, psychological, social, and spiritual needs of patients and families. The best definition of palliative care is that it is the kind of care we would want for our loved ones. It is the care that nurses have defined, imagined, and brought to life through expert clinical practice and scholarship. This edition reflects the broad terrain of our care, the ever-growing populations in need of palliative care and the solid evidence base for our practice.

Betty Ferrell and Judith Paice

Acknowledgments

We are grateful for the authors of the 76 chapters in this textbook. Their writing and their careers have built the discipline of Palliative Nursing and each chapter is a labor of love and dedication to better care for seriously ill patients and families. We also thank Andrea Hayward and Ellen Friedmann whose editorial assistance on every chapter of this text helped to create this textbook to guide the practice of nurses around the world.

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SECTION I

General Principles

CHAPTER 1

Introduction to Palliative Care

Betty Rolling Ferrell

Key Points

- Palliative care is a vital and necessary tool for nurses caring for an aging population.
- Properly assessing and managing the symptoms of chronic and advanced disease ensures that patients have the best quality of life possible during their illness journey.
- Psychosocial support and spiritual care are a fundamental part of palliative care that supports patients and families and helps them find hope and meaning in illness and in death.
- Palliative care must be made available to special patient populations: the poor, the homeless, the elderly, the drug-addicted, veterans, and those patients affected with mental illness among others.

The Textbook as a Resource

This fifth edition of the *Textbook of Palliative Nursing* comes at a time when palliative care is at the center of a healthcare system in need of urgent solutions to overwhelming challenges. An aging population, an uncertain healthcare payment system, growing chronic illnesses, and escalating costs have created opportunities to extend palliative care into settings and populations which were not even thought of when the last edition of this Textbook appeared only a few years ago.

Since the first edition of the Textbook in 2001, our hope as editors has always been that it would serve as an evidence-based resource for nurses searching for practical applications at the bedside. I keep a copy at my desk, at arms-length. Over the years, my own quality measure of the book has been to reach for it often to see if I can find useful information as I address daily questions in my professional life as a nurse and researcher. Almost always, I find the Textbook to, indeed, be a resource to answer real questions from real clinicians about real patients and families.

The Patient

The true test of the Textbook occurs at the bedside. Does this book really tell the story of the people we serve? As you read its pages, can you see the face of the patient?

As I prepared to edit this fifth edition, I had the opportunity to be involved in the care of an 85-year-old woman, Grace, who had chronic obstructive pulmonary disease (COPD). I had known Grace for approximately 5 years and witnessed her pulmonary disease progress from a well-managed chronic illness to become a life-altering disease that tried hard to squelch her radiant spirit and succeeded only in the last days of her life.

Grace was born and lived in Europe for the first 20 years of her life. She was a tall, beautiful, spirited woman whose last job before coming to America was as a flamenco dancer in a cabaret—quite a colorful job for a woman in 1950. She came to the United States for further adventure and began a long career as a "Girl Friday" in the movie studios of Hollywood. The next decades were filled with what she recalled as a wonderful life, filled with travel, interesting friends, constant stimulation, and glamour. Grace herself was a picture of glamour—she was tall and graceful, always impeccably dressed, and never without her French perfume.

At the age of 60, Grace was diagnosed with uterine cancer, and her fast-paced life came to an abrupt halt as she endured surgery and chemotherapy. She recovered completely but never returned to work. She did continue to enjoy her Hollywood friends, lunches, and travel to her family home in Europe.

Her zest for life was matched by a very deep religious faith, born from a devout Anglican religious upbringing from childhood. She was a person whose life was full of friends, family, cherished memories of her career, and a desperate desire to maintain her independence and her dignity.

Grace's pulmonary disease, which she attributed to the Hollywood days of women smoking, slowly took over her life. Her frequent respiratory infections limited her outings, and she eventually became oxygen-dependent. Although her body began to decline, her spirit persisted, and I watched over the course of the last 5 years of her life as the COPD took its toll on this beautiful woman and threatened her survival.

Grace insisted on living alone and refused assistance in her home. She had one short stay in assisted living after a hospitalization but then left the facility against all advice. She was determined to have her privacy at home. Fortunately, she was part of a healthcare system that seemed perfectly in step with Grace's needs. She received home care services and then later progressed to home-based palliative care. The palliative care team was astute in recognizing her decline over her last year of life but was also respectful of her intense need for independence.

Her COPD then seemed to advance over the course of a couple of months with several bouts of pneumonia and resultant challenges with dyspnea, insomnia, fatigue, and anorexia. She gave in and finally accepted the help of nursing assistants in her home, largely motivated by her desire to be well-dressed and to maintain her appearance despite the obvious decline in her body. One of her last outings was to attend a book signing by a Hollywood celebrity she had admired for years, a man who had just published his memoirs. This 85-year-old dyspneic, cachectic woman was transformed back into a young ingénue, totally enamored by a leading man.

A few months before Grace died, while visiting her at home, I noticed that she had recently framed a photograph of herself with a man, a picture that was probably taken of her in her late 20s. When I asked about the photo, she became very uncharacteristically quiet and serious and then she said, "I have loved three men in my life." I sat silently, recognizing that the person before me was reflecting deeply on her life. What followed was a lovely conversation as I listened intently and she told me about each of her three loves. As the stories were shared, I listened to this elegant woman tell her life story of loves, losses, betrayals, of good choices and bad; I heard this woman grieve for children she had never had, of her life that was both full and vibrant, but at times a life that was lonely and unfulfilled.

Just a few weeks before Grace died, the home-based palliative care program advanced her care into the hospice program. She remained in her home after finally accepting 24-hour care: her symptoms were well-controlled, and she insisted on getting all her affairs in order, advance directives completed, and everything well-organized—the perfect "Girl Friday" to the end.

My last visit with Grace was 6 days before she died. I had visited her over the years in my role as a volunteer and Eucharistic visitor through our shared faith community. We talked about her declining health, I shared communion with her, and we ended the visit by her telling me about her days as a flamenco dancer. It was the perfect last visit. Her death was peaceful, calm, and "Graceful."

The Textbook

Grace is in so many ways the model case example of the palliative care patients that we serve at the time of publication of this 5th edition of the Textbook. She represents an aging population, a person who has survived serious illnesses but has lived long enough to develop other serious illnesses with a prolonged trajectory of care.

How can this Textbook guide nurses to care for the "Graces" in our service? I think of Grace as I look over the contents of this book. Section I of the book presents General Principles, including chapters on national palliative care guidelines, hospital-based palliative care, principles of patient and family assessment, communication, and advance care planning. This section includes a chapter on palliative care team effectiveness, which is very reflective of the care Grace received. Her final months of life could have been quite different as a person with COPD, living alone, and at great risk of dying hospitalized and with severe uncontrolled symptoms.

Section II of the Textbook is on symptom assessment and management. Grace, like so many of our patients, at some point in her illness probably had almost every symptom listed across the 23 chapters in Section II. As these chapters illustrate, her care was dependent on competent symptom assessment, the best of pharmacologic and nonpharmacologic treatments, and attention to side effects such as pain, fatigue, anorexia, cachexia, dyspnea, and a whole host of other debilitating medical sequelae.

Section III of the Textbook introduces psychosocial and spiritual support, areas also critical to the whole-person care Grace needed and the care that all patients deserve. The chapters focus on spiritual care assessments and interventions, concepts of hope and meaning at the end of life, supporting families through the dying process and bereavement, and planning for actual death.

Section IV addresses the unique needs of Special Patient Populations. This part includes chapters addressing issues such as culture; older adults in the community; the poor, homeless, and underserved; veterans; and other populations in special need of palliative care, such as patients with mental illness or personality disorders, drug-addicted patients, AIDS patients, and pulmonary/critical care and heart failure patients. This section also includes chapters on organ donation and cancer survivorship, so important today to many receiving palliative care.

The fifth section reviews palliative care across settings. Grace—not at all distinct from most patients living with serious illness—was cared for across many settings, including home care, home-based palliative care, hospice, the intensive care unit, the emergency department, and the outpatient setting. This Textbook is dedicated to providing excellent care for patients across all settings of care and recognizes that nurses are the constant in each setting. This unit also addresses palliative care in rural communities; improving the quality of care across all settings; the role of the nurse caring for patients receiving palliative surgery or chemotherapy; and the role of PT, OT, and other palliative care therapies. This edition includes a new chapter on value-based care. Grace's care was not only high-quality care that met her needs but also delivered by a coordinated system that undoubtedly avoided costly admissions, futile care, and truly reflected her values and goals.

Section VII, Special Issues for the Nurse in End-of-Life Care, recognizes that nurses, as the ever-present support for end-of-life patients, encounter ethical considerations unique to this type of care and that they serve as advocates for this very vulnerable population. The chapters in this section address the need for nurses to practice self-care, the importance of nursing education and research, the role of the advanced practice nurse, the concept of caring in palliative nursing, and palliative care on the global scale of today's world.

Summary

As this fifth edition of the Textbook is published, I will again apply the "arm's-length" test of quality. As with earlier editions of the Textbook, this edition will be within easy reach in my office as I address the daily questions of nursing and research that arise in my professional life. I am confident that this book reflects the care that patients like Grace need and deserve and that it will serve as a valuable tool for the palliative care nurse at the bedside.

CHAPTER 2

National Consensus Project for Quality Palliative Care

Assuring Quality Palliative Care through *Clinical Practice Guidelines*

Constance M. Dahlin

Key Points

- The National Consensus Project for Quality Palliative Care (NCP)'s *Clinical Practice Guidelines* promote access to and the development of comprehensive quality palliative care through the delineation of eight key domains of care.
- The NCP's *Clinical Practice Guidelines* are the basis of specialty palliative care certification for hospitals, hospices, and home health agencies as well as professional certifications.
- The NCP's *Clinical Practice Guidelines* are the foundation of specialty palliative care education.

The National Consensus Project Initiative

The poor status of care at end of life and dying in America was the backdrop for the development of the National Consensus Project for Quality Palliative Care (NCP). Shortly after the Institute of Medicine (IOM)'s two separate reports on dying in America for adults in late 1997 and children in early 2000, national discussion began about how to improve care.[1,2] With hospice care already codified within the Medicare Hospice Benefit, a strategy to create guidelines for people ineligible for hospice, but palliative care–appropriate, was essential. In 2001, hospice and palliative care leaders convened in New York City to discuss standards in palliative care to guide the growth and expansion of palliative care in the United States. This meeting laid the foundation for the creation of the NCP (Box 2.1).

The first edition of the *Clinical Practice Guidelines for Palliative Care* was published in 2004. In 2005, the structure of the NCP moved to one of collaborative governance under the National Coalition of Hospice and Palliative Care. In 2006, the National Quality Forum (NQF) used the *Clinical Practice Guidelines* as a basis of its document *A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report*.[3]

With a mission to "improve American healthcare through the endorsement of the consensus-based national standards for measurement and public reporting of healthcare performance data,"[3] this adoption by NQF was significant in its support of hospice palliative care standards and preferred practices, with implications for reimbursement, internal and external quality measurement, regulation, and accreditation.[3]

In 2009, just 5 years after the initial release of the NCP *Clinical Practice Guidelines*, the landscape of palliative care had changed. The number of palliative care and hospice programs had substantially

Box 2.1 History of the National Consensus Project for Quality Palliative Care *Clinical Practice Guidelines*

2001	Meeting in New York City of national palliative care leaders.
2002	Development of the clinical guidelines.
2003	Initial Review by advisory committee.
2003	Release of the first edition of the *Clinical Practice Guidelines for Quality Palliative Care* in March at the Annual Assembly received official endorsement by 40 organizations and associations.
2005	Disseminated to 90 organizations and associations.
2006	Served as the basis of NQF's document *A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report.*
2009	Release of the second edition of the *Clinical Practice Guidelines for Quality Palliative Care* at the Annual Assembly of the American Academy of Hospice and Palliative Medicine (AAHPM) and the Hospice and Palliative Nurses Association (HPNA). Aspects of palliative care featured in review of healthcare reform under the Obama administration.
2011	The *Clinical Practice Guidelines for Quality Palliative Care* used as underlying principles for the Joint Commission *Advanced Palliative Care Certification.*
2013	Release of the third edition at the Annual Assembly of the AAHPM and HPNA endorsed by 54 organizations and associations.
2017	Funding for the creation of community-based palliative care guidelines specific to care in the home, skilled facility, assisted-living facility, group homes, shelters, prisons, etc.
2018	Expected completion of new guidelines with specific attention to palliative care in the community.

Box 2.2 National Consensus Project Clinical Practice Guidelines: Eight Domains of Care

Domain 1: Structure and processes of care
Domain 2: Physical aspects of care
Domain 3: Psychological and psychiatric aspects of care
Domain 4: Social aspects of care
Domain 5: Spiritual, religious, and existential aspects of care
Domain 6: Cultural aspects of care
Domain 7: Care of the patient nearing the end of life
Domain 8: Ethical and legal aspects of care

grown. Palliative care had become part of the national discussion of healthcare reform, making it necessary to assure concordance between the NCP *Clinical Practice Guideline* and the NQF *Framework and Preferred Practices*. Moreover, many stakeholders needed direction in implementing the conceptual ideas of the NCP *Clinical Practice Guidelines* into practice. As part of the commitment to have the guidelines reflect changes in palliative care, healthcare policy, and healthcare research, the guidelines were updated.

Within the review process, all 38 of the NQF preferred practices were reflected within the domains of palliative care. To broaden the scope of the document, there was appraisal and discussion within special interest focus groups related to palliative care (i.e., pediatrics, social work, oncology, geriatrics) to assure that the guidelines were representative of practice.[4] To ensure the inclusivity and expansiveness of the guidelines to all settings where palliative care is provided, clarifications were made and sections were further developed.[4] Finally, an updated palliative literature search was performed which yielded more articles specific to the American landscape.

From 2009 to 2013, significant maturation within the field of palliative care occurred. The numbers of hospice and palliative care programs across the nation with increased representation across healthcare systems and settings grew extensively. Although hospice and palliative nursing had been formally recognized as a specialty by the American Nurses Association for more than 20 years, palliative medicine was formally recognized by the American Board of Medical Specialties in 2008, establishing it as a distinct and well-defined subspecialty of care within healthcare. Palliative care research demonstrated that the presence of palliative care improved quality of life, decreased psychological symptoms, and perhaps increased survival. Healthcare reform included critical elements of palliative care and the establishment of a national palliative care quality measurement strategy within the United States through the Center for Medicare and Medicaid Services[5] (see Box 2.2).

National Consensus Project for Quality Palliative Care: Definitions and Tenets

In order to promote consistency, the NCP supports the palliative care definition developed by the Center for Medicare and Medicaid Services (CMS), which states:

> Palliative care means patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.[6]

In addition, several underlying palliative care tenets are delineated by the NCP[7]:

1. Palliative care is patient- and family-centered care.
2. Palliative care is comprehensive, with continuity and access across health settings.
3. Early introduction of palliative care concepts should begin at diagnosis of a serious or life-threatening illness by the primary team. Specialist consultation may be offered as well.
4. Palliative care may be offered concurrently with or independent of curative or life-prolonging care. Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death.
5. Palliative care is interdisciplinary and collaborative. Patients, families, palliative care specialists, and other healthcare providers collaborate and communicate about care needs.
6. Palliative care team members have clinical and communication expertise.
7. The goal of palliative care is the relief of physical, psychological, emotional, and spiritual suffering of patients and families.
8. Palliative care should focus on quality care.
9. There should be equitable access to quality palliative care services across geography, health settings, patient populations, and conditions.

At the outset, the mission of the NCP was to create clinical practice guidelines to ensure the quality of palliative care in the United States. The goal for the *Clinical Practice Guidelines for Quality Palliative Care* was to (1) to promote quality and reduce variation in new and existing programs, (2) develop and encourage continuity of care across settings, and (3) facilitate collaborative partnerships among palliative care programs, community hospices, and a wide range of other healthcare delivery settings.[8]

The development process was fourfold. First, there was a review of all international standards and guidelines. This included, most notably, those from Canada, Australia, Scotland, and Great Britain, where palliative care was established. From this, basic assumptions about palliative care were constructed. Second, a thorough review of the literature in hospice and palliative care was performed to support the guidelines. Since the Medicare Hospice Benefit is unique to the United States, it changes the dynamic of palliative care implementation. Because palliative care was in its infancy in the United States, there was little American literature specific to it, so evidence was borrowed from other countries and specialties. It was understood, however, that the guidelines would be changed with the evolution of the evidence base for palliative care, US healthcare reform, and professional practice. Third, a broad range of interdisciplinary experts across settings and populations was convened to develop consensus in quality palliative care delivery across the healthcare continuum. In considering quality, it was agreed that palliative care interdisciplinary team members would observe established professional and organizational codes of ethics. In addition, palliative care services would adhere to established standards and requirements for healthcare quality in safety, effective leadership, medical record keeping, and error reduction. Fourth, an inclusive writing process was created that role-modeled the collaborative process and underscored the importance of the project.[8] The NCP members reviewed the document line by line, with each sentence necessitating at least 80% agreement of task force members before inclusion.

An overall goal was that the guidelines would acknowledge specialty palliative care versus primary palliative care. Primary palliative care could be incorporated into any discipline in order to assure competency in symptom management and communication skills. Specific specialty palliative care qualifications would continue to be delineated by specialty organizations granting professional credentials and programmatic accreditation. A core assumption is that ongoing professional palliative care education (knowledge, attitudes, and skills) would occur to assure the delivery of quality palliative care across the domains established in the document.[8]

Thus, the *Clinical Practice Guidelines* are a framework for program development and a blueprint for existing programs to use to measure their quality. Rather than set minimally acceptable practices, the guidelines set ideal practices and goals that palliative care services should strive to attain. Upon the completion of each edition, a review process across healthcare and consumer organizations occurs. The result is both an assurance that the guidelines reflect the field and a formal endorsement process.

The Eight Domains of the *Clinical Practice Guidelines*

The NCP delineates eight domains of care and supports the goal of each domain with both available palliative care literature and other related literature from other specialties (see Box 2.2). Articles specific to each domain were published in a variety of journals (see Box 2.3).

Box 2.3 Domains and Articles Specific to the Domain

Domain 1: Structure and Processes of Care

Ferrell B. Overview of the domains of variables relevant to end-of-life care. *J Palliat Med*. 2005;8(S1):S22–S29.
Ferrell B, Connor S, Cordes A, et al. The national agenda for quality palliative care: the National Consensus Project and the National Quality Forum. *J Pain Symptom Manage.* 2007;33(6):737–744.

Domain 2: Physical Aspects of Care

Blouin G, Fowler B, Dahlin C. The National Agenda for Quality Palliative Care: promoting the National Consensus Project's domain of physical symptoms and the National Quality Forum's preferred practices for physical aspects of care. *J Pain Palliat Care Pharmacother.* 2008;23(3):1–7.
Dahlin C. Promoting culture within pain and palliative care: National Consensus Project guidelines and National Quality Forum preferred practices. *Am Acad Pain Manage/ Pain Practitioner.* 2007;17(2):7–9.

Domain 3: Psychological and Psychiatric Aspects of Care

Hultman T, Reder ER, Dahlin C. Improving psychological and psychiatric aspects of palliative care: the National Consensus Project and the National Quality Forum preferred practices for palliative and hospice care. *Omega.* 2008;57(4):323–339.

Domain 4: Social Aspects of Care

Altilio T, Otis-Green S, Dahlin C. Applying the National Quality Forum preferred practices for palliative and hospice care: a social work perspective. *J Soc Work End-of-Life.* 2008;4(1):3–16.

Domain 5: Spiritual, Religious, and Existential Aspects of Care

Scott K, Thiel M, Dahlin C. The national agenda for quality palliative care: the essential elements of spirituality in end-of-life care. *Chaplaincy Today.* 2008;24(2):15–21.
http://www.professionalchaplains.org/files/publications/chaplaincy_today_online/volume_24/number_2/24_2scott.pdf
Accessed January 7, 2018.

Domain 6: Cultural Aspects of Care

Dahlin C. Promoting culture within pain and palliative care: National Consensus Project Guidelines and National Quality Forum preferred practices. *Am Acad Pain Manage/Pain Practitioner.* 2007;17(2):7–9.

Domain 7: Care of the Patient Nearing End of Life

Lynch M, Dahlin C. The National Consensus Project and National Quality Forum preferred practices in care of the imminently dying—implications for nursing. *J of Hosp Palliat Nurs.* 2007;9(6):316–322.

Domain 8: Ethical and Legal Aspects of Care

Colby WH, Dahlin C, Lantos J, Carney J, Christopher M. The National Consensus Project for quality palliative care Clinical Practice Guidelines Domain 8: ethical and legal aspects of care. *HEC Forum.* 2010;22(2):117–131.

Domain 1: Structure and Process of Care

This domain addresses the organization of specialty palliative care teams and the necessary processes and procedures for quality care delivery.[7] The criteria emphasize coordinated assessment and continuity of care across healthcare settings. In particular, there is a description of the interdisciplinary team composition, team member qualifications, and necessary education, training, and support. There is attention paid to and emphasis on interdisciplinary team engagement and collaboration with patients and families. Finally, the domain incorporates the new mandates for quality as established within healthcare reform, which will continue to evolve. Palliative nurses need to understand specialty palliative care delivery as defined by specialty palliative care nursing qualifications, including certification through the Hospice and Palliative Credentialing Center, educational requirements, and communication. Palliative care nurses also need to understand the essential aspects of interdisciplinary care delivery and collaborative team processes.

Domain 2: Physical Aspects of Care

This domain recognizes the multidimensional management of symptoms using pharmacological, interventional, behavioral, and complementary interventions. There is emphasis on the assessment and treatment of physical symptoms using appropriate, validated tools. Finally, there are recommendations for the use of explicit policies for the treatment of pain and symptom management, the use of multimodal strategies and safe prescribing, and safe storage and disposal of controlled medications.[7] Palliative nurses must be educated in the range of pharmacological and nonpharmacological guidelines to provide safe pain and symptom management, particularly within the current opioid misuse crisis.

Domain 3: Psychological and Psychiatric Aspects of Care

This domain acknowledges the psychological and psychiatric dimensions of palliative care. It reviews the collaborative assessment process of these diagnoses, similar to that for the multidimensional approach to physical aspects. It defines essential elements including patient–family communication on assessment, diagnosis, and treatment options in the context of patient and family goals of care. Again, multimodal strategies are encouraged. Most significantly, this domain includes required criteria for a bereavement program. Palliative nurses need to understand that psychological and psychiatric aspects of care are as important as the physical aspects. Moreover, nurses must consider a bereavement plan because care continues for the family after death through the provision of bereavement care.

Domain 4: Social Aspects of Care

This domain emphasizes interdisciplinary engagement and collaboration with patients and families to identify support within the organization and the community to capitalize on patient and family strengths. It defines essential elements of a palliative care social assessment. Notably, it includes the description of the role of the bachelor's- or master's-prepared social work professional. Palliative nurses need to focus on family systems to support person-centered and family-focused care. In addition, they need to collaborate with social work and integrate the expertise of their social work colleagues.

Domain 5: Spiritual, Religious, and Existential Aspects of Care

This domain has evolved to include a spirituality definition. While simultaneously stressing interdisciplinary responsibility and collaboration in assessment and management of spiritual issues and concerns, there is emphasis on the use of an appropriately trained chaplain. Requirements for staff training and education in spiritual care are described. Finally, the domain promotes spiritual and religious rituals and practices for comfort and relief.[7] Palliative nurses need to understand the range of the spiritual component, whether it is ritualized or not, and its impact on care. In addition, they need to collaborate with spiritual care providers and integrate the expertise of their chaplain and spiritual leader colleagues.

Domain 6: Cultural Aspects of Care

The development of this domain now includes a definition of required interdisciplinary team culture and cultural competence, highlighting culture as a source of resilience and strength for the patient and family. Cultural and linguistic competence with respect to language, literacy, and linguistically appropriate service delivery is stressed.[7] Palliative nurses need to understand the cultures of the communities they serve. Palliative nurses also need to consider the breadth of cultural competence outside their own worldview and embrace cultural care beyond the use of an interpreter service.

Domain 7: Care of the Patient Nearing End of Life

The title of this domain has changed from Care of the Imminently Dying to Care of the Patient at the End of Life to broaden care to advanced stages of illness through death. In particular, it emphasizes the social, spiritual, and cultural aspects of care throughout the dying trajectory for the patient. It underscores the importance of meticulous assessment and management of pain and other symptoms. The importance of communication, information, and documentation of the signs and symptoms of the dying process, inclusive of the patient, the family, and all other involved health providers, is underscored.[7] Palliative nurses need to promote this nursing expertise and assure quality care at this time.

Domain 8: Ethical and Legal Aspects of Care

This domain is separated into three sections: advance care planning, ethics, and the legal aspects of care. The responsibility of the palliative care team to promote ongoing goals of care discussions accompanied by completion and documentation of advance care planning is emphasized. Significant is the affirmation and acknowledgment of the frequency and complexity of palliative care ethical and legal issues. Consultation from ethics committees and legal counsel are stressed, as are team competencies in ethical principles and education regarding particular legal aspects of care. There is also emphasis on the understanding of the respective scopes of practice issues among team members.[7] The use of ethics and legal resources could help diminish moral distress for nurses as well as for all healthcare professionals. Palliative nurses need to understand the scope of their care and the boundaries of ethics, as well as the resources available to provide care in this important specialty.

Implementation of the *Clinical Practice Guidelines*

Since 2013, developments have occurred in the field that have spurred further refinement of the guidelines. In 2014, the IOM released its report, *Dying in America—Improving Quality and Honoring Individual Preferences Near End of Life*. It highlights five areas in which to assure quality palliative care:

- delivery of person-centered and family-focused palliative care,
- clinician–patient communication and advance care planning,
- professional education in palliative care,
- policies and payment for palliative care, and
- public education and engagement in palliative care.[9]

In terms of the delivery of patient-centered and family-focused palliative care, the *Clinical Practice Guidelines* domains have grounded care within various populations. Various professional organizations have delineated the role of palliative care, as in the care of patients with amyotrophic lateral sclerosis (ALS), heart disease, stroke, and dialysis.[10–12] This is particularly true in oncology care. The American Society of Clinical Oncology (ASCO) delineated quality standards using NCP guidelines within cancer care[13] (see Box 2.4). More recently, the guidelines have been applied to patients entering cancer clinical trials.[14] Other populations include those with pulmonary disease and cystic fibrosis, in which the guidelines grounded the role of palliative care.[15,16] The quest to develop quality perinatal palliative care resulted in the use of the NCP domains as the basis of a survey of perinatal programs across the United States and a tool for parents of infants in palliative care.[17,18]

Many clinician–patient communication and advance care planning initiatives have been grounded in the guidelines. The NCP guidelines also served as an important document to promote international and national consensus for the spiritual aspects of whole-person care.[19] And there have been several initiatives related to the NCP domain which focus on communication, including Comfort Communication,[20] Vital Talk,[21] and The Serious Illness Project.[22,23] An initiative related to the Ethical and Legal Aspects of Care domain, which focuses on advance care planning and engagement, is The Conversation Project.[24]

Professional education in palliative care has used the NCP framework to develop curriculum. This includes the End-of-Life Nursing Education Consortium (ELNEC) for nurses[25] and Education in Palliative and End-of-Life Care (EPEC) for physicians.[26] Professional organizations have used the guidelines for the creation of specialty practice. The National Association of Catholic Chaplains used them to create their certification program.[27] The Physicians Assistants Association is using them to create a palliative care specialty within its discipline.[28] The Society of Palliative Pharmacists used them to delineate the important role of pharmacists on the team.[29]

Box 2.4 Professional Organization with Palliative Care Guidelines

American Society of Clinical Oncology: Palliative care at cancer diagnosis
American Heart Association and American Stroke Association: Cardiovascular disease and stroke
American Academy of Neurology: Amyotrophic lateral sclerosis (ALS)
Renal Physicians Association and American Society of Nephrology: Initiation of and withdrawal of dialysis

A major body of work in palliative care has focused on the development of quality measures to demonstrate the value and effectiveness of palliative care. As was the intent of their creation, the NCP *Clinical Practice Guidelines* have served as the basis for the development of specific measures and a research agenda.[30–32] One program is Measuring What Matters, a joint initiative between the American Academy of Hospice and Palliative Medicine (AAHPM) and the Hospice and Palliative Nurses Association (HPNA), which reviewed the domains to create their profile of measures.[33] The PEACE measures that evaluate quality in hospices and palliative care also used the domains.[34]

In assuring quality of programs, The Joint Commission initiated Advanced Palliative Care Certification beginning in 2011 for hospitals, using the NCP *Clinical Practice Guidelines* as benchmarks to measure the breadth and depth of palliative programs.[35] In 2016, the Joint Commission added certification in palliative care for the community and offered a Community-Based Palliative Care Certification to home health agencies and hospice organizations, as well as hospitals.[36] In order to meet these standards and assure quality care delivery, many programs have made the case for including all essential team members, particularly from social work and chaplaincy, as integral members of specialty palliative care teams.

Although the guidelines have been applicable to all populations across all settings, over the past few years there has been a growing emphasis placed on care outside the hospital and in the community. To that end, there has been discussion in having guidelines that reflect the opportunities and challenges in the community. One study on guidelines in the community suggested that there could be more in the domains on social issues to reflect the experiences of patients as well of those of the caregiver.[37] Another study matched the guidelines to person-centered goals in serious illness.[38] Finally, the Connecticut Coalition to Improve End-of-Life Care used the guidelines to determine community proficiency in end-of-life (EOL) care.[39]

Given the rapidly changing healthcare landscape, palliative care is quickly expanding. A new revision of the guidelines is in process that includes a deliberate broadening of partnerships with constituents from clinical providers, community service providers, payers, and professional clinical and consumer organizations. A summit meeting was held in 2017, with 58 representatives from organizations across the country gathering to gain further input on the growing trend of care in the community.[17] Moreover, the next edition of the guidelines will be inclusive of both primary palliative care and specialty palliative care.[28]

National Consensus Project *Clinical Practice Guidelines*: Implications for Nursing

Nursing and palliative care are intertwined. Recognition of specialty palliative nursing expertise and assuring the quality of palliative nursing practice are essential to quality palliative care. Nurses practice in a variety of settings that may have palliative care programs. The NCP *Clinical Practice Guidelines* establish essential elements of specialist palliative care that promote quality, consistent clinical services. In particular, the guidelines assure clear expectations of high-quality nursing practice, including orientation, job descriptions, and peer review.

The 2011 IOM report *The Future of Nursing: Leading Change, Advancing Health* acknowledged the essential contributions of nursing at the bedside and in healthcare redesign in its four messages[40]:

1. Nurses should practice to the full extent of their education and training.
2. Nurses should achieve higher levels of education and training through an improved education system that promotes seamless academic progression.
3. Nurses should be full partners, with physicians and other healthcare professionals, in redesigning healthcare in the United States.
4. Effective workforce planning and policymaking require better data collection and information restructure.[22]

The NCP *Clinical Practice Guidelines* promote these messages and delineate quality in three areas particularly appropriate for nursing and consistent with the IOM report: professional development, education, and certification. The *Clinical Practice Guidelines* offer a framework to care, educational areas, and criteria for benchmarking nursing. The guidelines are a framework applicable to nurses across settings ranging from acute care, ambulatory care, rehabilitation facility, community, home care, and hospice programs, to long-term care facilities, accountable care organizations, and patient medical homes.

As a quality imperative, the NCP *Clinical Practice Guidelines* can result in improved patient outcomes and better compliance with state and federal regulations. Because appropriate resource utilization is a common concern, the emphasis on community assessment and communication across settings and specialties may provide a nursing benchmark. Moreover, the strict description of pain and symptom assessment, management, the use of assessment tools, and evidence-based practice is significant, particularly with regard to the opioid crisis. These criteria may promote safe nursing practices and improved patient and family satisfaction in pain and symptom control.

Domain 2, Physical Aspects of Care, and Domain 3, Psychological and Psychiatric Aspects of Care, may help organizations meet evidence requirements for the American Nurses Credentialing Center Magnet Status Recognition Program in the areas of Structural Empowerment, concerning nursing image and professional development; Exemplary Professional Practice, concerning consultation and resources, autonomy, and interdisciplinary relationships; New Knowledge, Innovation, and Improvements, concerning quality improvement; and Empirical Quality Results, concerning quality of care.[41] They can also facilitate accreditation by The Joint Commission in the areas of pain management, culturally competent care, and EOL care. Again, they may also help the nurse promote higher patient satisfaction and patient experience.

Domain 4, Social Aspects of Care; Domain 5, Spiritual, Religious, and Existential Aspects of Care; and Domain 6, Cultural Aspects of Care coach the nurse to deliver more effective and culturally competent care by focusing care on the patient and family system. This is particularly important in the landscape of rapidly changing population demographics. Domain 7, Care of the Patient Nearing End of Life, is an area of nurse expertise and helps nurses coach and mentor one another in this area. Domain 8, Ethical and Legal Aspects of Care, broadens the support system of the nurse by including both an ethics committee and a legal counsel in advocating for the patient and/or family.

The NCP *Clinical Practice Guidelines* have been used for many palliative nursing educational initiatives, particularly within the HPNA. First, in the *HPNA Standards for Clinical Education of Hospice and Palliative Nurses*, the *Clinical Practice Guidelines* serve as the basis for palliative nursing educational activities for nurses including observerships, practicums, preceptorships, residencies, fellowships, and immersion courses.[42] Second, HPNA has created a resource for both the registered nurse (RN) and the advanced practice registered nurse (APRN) that delineates the implementation of the guidelines.[43,44] Third, the HPNA created *Palliative Nursing Manuals* based on the NCP domains. In collaboration with Oxford University Press and using the *Oxford Textbook of Palliative Nursing*, eight *Palliative Nursing Manuals* promote quality practice and excellence in the domains.[45] Fourth, the NCP guidelines serve as the basis for the HPNA RN Pathway and APRN Pathway, which are currently in development and will be available in 2019. The pathways use the Benner Novice to Expert Framework for an RN or APRN to develop from a novice to an expert palliative nurse by grounding the education in the NCP guidelines.

Other essential nursing education courses use the NCP. The *Clinical Practice Guidelines* frame the ELNEC curricula in demonstrating best practices.[46,47] The guidelines serve as an underpinning to nurse-specific roles and skills. The American Association of Colleges of Nursing and the City of Hope utilized the NCP in the development of *CARES: Competencies and Recommendations for Educating Undergraduate Nursing Students: Preparing Nurses to Care for the Seriously Ill and Their Families*.[48] To accompany this, they have created an educational program based on these competencies for utilization within all undergraduate and pre-licensure nursing programs. In another project, the NCP domains serve as the structure for an intervention to improve nurses' skills in palliative care.[49] Lindley, Herr, and Norton use the NCP domains to describe the role of hospice and palliative care nurses in quality improvement.[50] Finally, in 2017, the American Nurses Association and the HPNA released *A Call For Action—Nurses Lead and Transform Palliative Care* in which the NCP guidelines ground palliative nursing in its fourth recommendation[51]:

> Advocate the use of the National Consensus Project for Quality Palliative Care *Clinical Practice Guidelines for Quality Palliative Care* in the development, implementation, and evaluation of specialty, evidence-based, palliative care services for all organizations.[51]

As an education tool, the guidelines offer content for specialty palliative nursing and promote more effective educational programs based on the evidence from research. Essential nursing education features include a focus on orientation, communication, pain and symptom assessment, social/cultural assessment, and spiritual assessment. The *Clinical Practice Guidelines* promote understanding of the domains (particularly bereavement and social, cultural, and spiritual care) and the essential nursing components in patient-centered care delivery. Just as important, the essential aspects of ethical foundations and legal regulations assist the nurse in scope-of-practice issues and mitigate moral distress by providing more clearly delineated processes for conflict resolution.

Conclusion

The NCP *Clinical Practice Guidelines for Quality Care* is a significant resource to facilitate collaborative care for patients with serious, debilitating, and life-limiting illnesses. It offers the palliative nurse a framework for comprehensive, quality, person-centered care across all settings within a community, ranging from home, assisted living, group homes, shelters, and nursing care facilities to adult and pediatric day care centers, community and senior centers, office and clinic practices, and acute hospital settings. It promotes care across all populations from neonates to children to adults and older adults; across the range of chronic progressive and serious life-threatening illnesses, injuries, and trauma; and across a range of vulnerable and underresourced populations (homeless individuals, immigrants, low-income individuals, oppressed racial and ethnic groups, veterans, prisoners, older adults, and individuals with mental illness).[21]

The NCP *Clinical Practice Guideline*s promote the growth and maturity of the field by facilitating the development and continuing improvement of clinical palliative care programs providing care to patients and families with serious illness; establishing uniformly accepted definitions of the essential elements in palliative care that promote quality, consistency, and reliability of these services; establishing national goals for access to quality palliative care; fostering performance measurement and quality improvement initiatives in palliative care services; and promoting continuity of palliative care across settings (i.e., home, residential care, skilled facility, long-term care setting, rehabilitation setting, hospital, and hospice).[7] They offer the foundation upon which nurses can create and develop quality palliative care and practice.

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CHAPTER 3

Hospital-Based Palliative Care

Patricia Maani-Fogelman

Key Points

- Hospital-based palliative care (HBPC) teams provide both an interdisciplinary and multidisciplinary component to the care of patients with advanced illness.
- HBPC teams can provide structured and ongoing care throughout the course of patient hospitalization and across care settings, from intensive care to medical surgical floor settings and nursing homes.
- Data analytics and care metrics provide support for continued HBPC programmatic growth.
- Nurses at all levels are vital to the ongoing delivery, management, and supportive care of the patient with advanced illness.

Case Study

Mrs. K was an 82-year-old retired nurse with rheumatoid arthritis, severe right heart failure/pulmonary hypertension (Group 2 and 3 disease) and left heart failure, heart block with pacemaker placement, renal failure, kyphoscoliosis, and obstructive sleep apnea. In the past year, she has had six admissions for acute or chronic hypoxemic respiratory failure. Serial echocardiograms demonstrated progressive right- and left-sided heart failure with rising estimated pulmonary artery pressures. She was not a candidate for advanced pulmonary hypertension therapies. Her hypoxemia worsened, and she required around-the-clock oxygen at higher flow rates. During the last admission, she became dependent on bilevel positive airway pressure (BiPAP) for ventilatory support and could not be weaned off this support. In past discussions with her pulmonary-palliative medicine nurse practitioner, she had verbalized the desire not to be sustained on artificial means of life support, to have a comfortable death at home (if possible), but, most importantly, to have her family present. During this admission, it became clear that she would not be able to wean off BiPAP. The pulmonary-palliative nurse practitioner had ongoing discussions with Mrs. K during daily inpatient rounds as well as family meetings held with Mrs. K, her husband, and adult children. She did not want to continue BiPAP, and a discharge home was not possible due to medical acuity. The pulmonary-palliative nurse practitioner provided ongoing support. Goals of care were discussed, Mrs. K's wishes for end-of-life (EOL) care were carefully navigated, and a plan was developed to transition Mrs. K from BiPAP to nasal cannula with supportive medications to assure relief of any respiratory distress. It was agreed that she would be provided with inpatient palliative and EOL care to assure that her end-of-life goals were met. The chaplain provided Mrs. K with the Sacrament of the Sick and Last Rites in accordance with her Catholic religion. Additional family came to visit. All her grandchildren were able to have private visits with her, where she dispensed her best advice and aspirations for their success in both life and love. When Mrs. K was ready, the nurse practitioner premedicated her with opioid for respiratory distress and secretion management. Opioid medication and anxiolytics were administered as the patient requested. Over the next few hours she became less interactive and less able to be aroused. When her respiratory symptoms became more intense, an opioid infusion was started for optimized symptom management and Mrs. K became visibly more comfortable. Her family was reassured, and they verbalized satisfaction with her care. Surrounded by her family and in no distress, Mrs. K passed away later that night.

A Brief History

The history of hospital-based palliative care (HBPC) is a long and evolving story. In 1978, Senator Edward Kennedy said "Hospice is many things. Hospice is home care with inpatient back-up facilities. Hospice is pain control. Hospice is skilled nursing. Hospice is a doctor and a clergyman coming to your home. . . . But most of all, hospice is the humanization of our health care system."[1] The number of US hospitals offering palliative care services has been increasing rapidly for more than a decade, many times in response to patient needs as well as healthcare and medical/nursing education reform (see Box 3.1).

While there has been a national trend indicating growth, the Center to Advance Palliative Care's (CAPC) 2015 State-by-State Report Card gives the nation a grade of B: the 2015 Report Card shows a continued increase in the number of hospital palliative care teams in the United States, with 67% of US hospitals (>50 beds) reporting palliative care teams, an increase of 10% from the 53% of hospital reporting the same in 2008.[2] This evidence supports the reality that, even with continued growth, access to palliative care remains inadequate for millions of patients living with advancing, chronic disease. While there is still room for improvement nationally, it is gratifying to know that the number of states with A grades (defined as more than 80% of the state's

Box 3.1 Milestones in the Evolution from Home Hospice to Hospital-Based Palliative Care

1970s: Awareness of hospice philosophy transfers from Great Britain to the United States

1976: Karen Ann Quinlan case

1980s: Recognition of aging population, chronic disease demographics, growth of National Institute on Aging and the American Association of Retired Persons

Passage of Medicare Hospice Benefit

Recognition of AIDS

1990s: National recognition in the United States of the problem of end-of-life care

1990: Nancy Cruzan case

1990–1997: Kevorkian-assisted deaths

1991: Patient Self-Determination Act

1995: SUPPORT study findings of poor end-of-life care

1997: Legalization of assisted suicide in Oregon

1997: Institute of Medicine (IOM) Report: "Approaching Death: Improving Care at the End of Life"

1997: Institute for Health Care Improvement (IHI) End-of-Life Breakthrough Collaborative

1998: First palliative care APN programs (Ursuline College, New York University)

1999: Kevorkian convicted of first-degree murder and imprisoned

2000s: Baby boomers with aging parents achieve positions of leadership and authority (Project on Death in America [pdia] scholars/leaders) entering and legitimizing palliative medicine as a specialty field

2001: Institute of Medicine Report "Improving Palliative Care for Cancer"

Public Broadcasting System (PBS) Bill Moyers Special, "On Our Own Terms"

1995–2003: Robert Wood Johnson Foundation funds end-of-life activities

Last Acts

Promoting Excellence in End-of-Life Care

Partnership for Caring

Educating Physicians in End-of-Life Care (EPEC)

End-of-Life Nursing Education Consortium (ELNEC)

Open Society/Project on Death in America (PDIA)

Faculty Scholars Program

2001: Disseminating End-of-Life Education to Cancer Centers (DELEtCC)

2002: Department of Veterans Affairs initiates multiple palliative/end-of-life programs

Mayday, Kornfeld sponsor mini-fellowships (Northwestern, Memorial Sloan Kettering, etc.)

Growth and development of specialty education and organizations

Shift of professional membership organizations from being homes of the isolated to active change agents in policy, education, and clinical change: HPNA, AAHPM

Center to Advance Palliative Care & Palliative Care Leadership Centers

NHPCO, AAHPM, HPNA—membership organizations

Palliative Medicine achieves ABMS specialty status

Advanced and NA specialty nursing certification

Expansion of Harvard course, EPEC, ELNEC, JPM

Development of (MD) fellowship programs

2004: National Consensus Project + 2008 NQF-Quality Guidelines

2005: Terry Schiavo case

2005: The American Heart Association and the American College of Cardiology release new guidelines about treating heart failure that includes recommendations that hospice care education be provided early in the course of an illness.

Research evidence to support palliative care emerging and developing new funding sources

NPCRC/ACS Junior Faculty & Pilot Project Awards

2008: The Joint Commission considers Palliative Care Certification process

2008–2014: California launches 5-year initiative "Spreading Palliative Care in Public Hospitals" to develop HBPC programs

2010: *New England Journal of Medicine* landmark study: "Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer."

2010: NHPCO Standards of Practice for Pediatric Palliative Care and Hospice Receives American Academy of Pediatrics' Affirmation of Value.

2010: We Honor Veterans, a pioneering campaign to help improve the care Veterans receive from hospice and palliative care providers, is launched by NHPCO in collaboration with the Department of Veterans Affairs.

2010: A provision in The Patient Protection and Affordable Care Act will require state Medicaid programs to allow children with a life-limiting illness to receive both hospice care and curative treatment.

Box 3.1 Continued

2011: The Joint Commission launches Palliative Care Certification.

2011: NHPCO publishes report, Private Conversations and Public Discourse: The Importance of Consumer Engagement in End-of-Life Care.

2011: The Concurrent Care for Children: Implementation Toolkit is released by NHPCO and the District of Columbia Pediatric Palliative Care Collaboration.

2011: Campaign for the National Center for Care at the End of Life Launched by National Hospice Foundation.

2011: Ethical Marketing Practices position statement and commentary are released by NHPCO.

2011: The bicameral Wyden-Roberts HELP Hospice Act is introduced in Congress. The Concurrent Care for Children: Implementation Toolkit is released by NHPCO and the DC Pediatric Palliative Care Collaboration.

2012: LIVE—Without Pain, a new public awareness campaign from NHPCO's Caring Connections, dispels myths about pain and empowers consumers.

2012: An innovative, online advocacy resource, the Legislative Action Center, is created online by the Hospice Action Network. More than 1.5 million people are reached through the six-part online video series, Basics of Hospice.

2013: Research from Mount Sinai's Icahn School of Medicine demonstrates cost savings of hospice and NHPCO and Hospice Action Network work to take this research to legislators and the media.

2014: FHSSA expands its mission and is re-launched as Global Partners in Care.

2017: Palliative Care and Hospice Education and Training Act, PCHETA, would amend the Public Health Service Act to increase the number of permanent faculty in palliative care education programs. S. 693, H.R.1676 (www.nhpco.org/history-hospice-care)

hospitals reporting a palliative care team) has increased, from 3% in 2008 to 17% in 2015; perhaps most significantly, for the first time, no state has a grade of F (defined as less than 20% of a state's hospitals reporting a palliative care program).[1] However, deficits in care remain an ongoing issue, with one-third of US hospitals (>50 beds) reporting no palliative care services and one-third of the states receiving a grade of C or D.[2,3]

The Aging Population

More than one-third of Medicare patients with advanced, chronic illness experience four transitions in care during their last year of life.[2,3] This burden is significantly higher in the Medicare population than in the general population; in the aged, the majority of deaths are attributable to common diagnoses: congestive heart failure, chronic lung disease, cancer, coronary artery disease, renal failure, peripheral vascular disease, diabetes, chronic liver disease, and dementia.[2–4] Their disease trajectory is chronic and progressive in the setting of advancing, incurable disease that will eventually reach a point of maximal medical therapies providing little to no benefit and continued failure. Palliative care teams provide consultation services to help manage complicated patients in the acute, subacute, and chronic illness setting. The HBPC team maintains a focus on management of pain and symptom issues through the course of the hospital admission. Palliative care teams focus on strong communication with the patient/family, primary and specialty teams, and the interdisciplinary team (IDT).

In 1974, the Royal Victoria Hospital in Montreal, Canada, developed one of the first initiatives in North America to improve HBPC. They created a palliative care service to meet the needs of hospitalized patients who were terminally ill within the general hospital setting.[5] An integral part of the Royal Victoria Hospital, a 1,000-bed teaching hospital affiliated with McGill University, the palliative care service consisted of five complementary clinical components: (1) the palliative care unit (PCU), (2) the home care service, (3) the consultation team, (4) the palliative care clinic, and (5) the bereavement follow-up program. Members of an IDT were involved with the care of these patients, and the focus was on holistic care with pain control and symptom management. Decades later, these basic palliative care concepts are more prevalent throughout US hospitals and the nation, and several milestones over the past four decades have shaped the evolution of care of the seriously ill. In the 1970s, the concept of home-based hospice programs (often volunteer-only) seen in Europe and Canada began to appear in the United States, imported from Europe and Canada. Since that time, several professional, medical, societal, and academic endeavors have coalesced in the form of HBPC programs that adapt and "upstream" principles of hospice care into mainstream medicine. Although there is no requirement for all healthcare systems to have such a program, palliative care is gradually being recognized as a "standard of care." For organizations that still need convincing, Meier[6] and the National Consensus Project[7] make the case for implementation of and early involvement of hospital-based palliative care (1) to improve clinical quality of care for seriously ill patients; (2) to increase patient and family satisfaction with care; (3) to meet the demand of a growing, chronically ill, elderly demographic; (4) to serve as "classrooms" for the next generation of clinicians to provide better care to the seriously ill; and (5) to provide value-added, cost-effective care in the face of a national healthcare and economic crisis.[6,7] Recent palliative care studies present a compelling argument that, based on the amount of available evidence, HBPC is state-of-the-art care.

Although much of the data to support the evolution of HBPC are derived from care deficits identified in hospitalized patients at the very end of life,[1–4] the goal of HBPC is to improve the quality of life (QOL) of persons with life-limiting illness early in the illness and across all settings of healthcare.[6–8]

Defining Palliative Care

While there have been variations in defining "palliative care," the Center to Advance Palliative Care today offers the most clarified and structured definition: "*Palliative care, and the medical subspecialty of palliative medicine, is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality* *of life for both the patient and the family. Palliative care is provided by a team of palliative care doctors, nurses, social workers and others who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment."* Palliative care utilizes a whole-person philosophy, seeking to examine factors beyond simply the person's diagnosis.[9]

The Center to Advance Palliative Care (CAPC) defines HBPC as "an interdisciplinary medical team focused on symptom management, intensive patient–physician–family communication, clarifying goals of treatment and coordination of care across health care settings." CAPC has identified a streamlined process to establish an HBPC program, which includes seeking expert guidance from validated sources (such as capc.org), establishing a planning committee with key stakeholders (hospital administrative leadership, providers from chronic disease programs, physicians, nurses, social workers, case management, spiritual care, and business/finance coordinators), collecting data that identify the needs of the patients at the institution (including deficiencies in care, transitions in care at end of life, analytics on pain/symptom management, length of stay, cost per day, and patient/family satisfaction), and reviewing the literature on palliative care impact, which can then be used to develop a business plan that can be integrated into action.[9]

In Temel and colleagues' (2010) landmark study, "Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer," lung cancer patients who received palliative care along with conventional treatment survived 2.7 months longer than patients who received only standard oncological care. Published by the *New England Journal of Medicine*, this study clearly demonstrated the value, need, and importance of palliative medicine interventions for patients with advanced, life-limiting illness.[10]

Ever since the increased national awareness and ongoing analysis of the availability of HBPC programs in 2000, there has been continued growth (as already mentioned, 67% of hospitals with 50 or more total facility beds offer palliative care). And there is a definite set of institutional characteristics associated with the presence of a HBPC program—bigger facilities are more likely to offer palliative care than smaller centers: 90% of hospitals with 300 beds or more had HBPC versus 56% of hospitals with less than 300 beds. Tax status was also a significant predictor: not-for-profit hospitals and public hospitals were, respectively, 4.8 times and 7.1 times more likely to have a palliative care program as compared to for-profit hospitals. In terms of geographic distribution, HBPC prevalence was highest in the New England states (88%), Pacific states (77%), and mid-Atlantic states (77%), and lowest in the west south central (43%) and east south central states (42%). Therefore, while access to HBPC improved, a deficit remains due to factors such as regionality and tax status.[2,11]

Standardizing Palliative Care in Hospitals

To assure standardization in HBPC delivery, the National Consensus Project (NCP) released the first palliative care clinical practice guidelines in 2004; these were updated in 2009 and 2013, and a new edition is scheduled for release in Summer 2018. The NCP identified eight Domains of Care (structure and processes, physical aspects, psychological/psychiatric aspects, social aspects, spiritual/religious/existential aspects, cultural aspects, care of the patient at end of life, and ethical/legal aspects) to assure consistent care delivery reflective of changes in the national healthcare arena of reform, as well as new outcomes research that defines best-practice elements for high-quality palliative care.[12]

Chronic illness and longer life was the legacy of the twentieth century. However, the healthcare system did not keep pace with medical advances, and the hospital remains the common location for EOL care despite Americans' stated preference for death at home.[13–15] Hospitals were designed primarily to provide acute, episodic care to persons with acute illness rather than comfort and continuity to persons who were not expected to survive a disease or episode of illness. Therefore, fundamental system reform and redesign is warranted to improve (and possibly prevent) hospital care of persons with life-limiting illness.

This is a call to action, particularly for nurses, since nursing care is the primary service provided during hospital admission, and much of the care and the system that patients experience can be influenced by nurses at all organizational levels. The way nurses learn and share their knowledge will further direct the process of patient care.[15,16] HBPC programs have begun to change the quality and quantity of hospitalized deaths as nurses evolve into the servant-leader role, defining and directing multi-/interdisciplinary teams and modifying efforts at multiple levels of the hospital care system to improve the complex care process for persons with life–limiting illness.[3,14-17] Improved palliative care structure, standards for care processes, and measurement of outcomes have begun as a result of the development of HBPC programs.

Quality of Care Issues

In an ideal world, discussion of advance directives should take place with patients when they are not in crisis. The early introduction of palliative care specialists may help to clarify and document patients' goals of care and pain/symptom management preferences. The HBPC teams can facilitate medical and nursing staff education about advance directives, palliative care, and EOL issues. Establishing baseline competence levels and protocols and policies to support identification of patients' goals of care will hopefully minimize unnecessary patient and staff suffering.

Barriers

The well-known barriers that block access to palliative care include[17]:

1. Lack of resources
2. Lack of knowledge about existing resources or provider reluctance to refer
3. Misunderstandings and/or lack of clear, effective understanding of palliative care
4. Provider bias, which includes the overall common reluctance to refer
5. Patient and/or family barriers created by reluctance
6. Restrictive specialist palliative care service program eligibility criteria

The inclusion of palliative care in the hospital can help avoid putting patients through unnecessary and often undesired interventions; this results in overall cost savings when resources are spent where they have the greatest potential to yield the best outcomes.[18]

Models of Hospital-Based Palliative Care

HBPC can be primary, secondary, or tertiary, and its promotion requires a myriad of resources. Depending on the model of palliative care being introduced, the required resources can vary greatly. For example, some changes may require financial support via construction or the addition of staff, whereas other changes are less resource-intensive. Regardless of the healthcare system and the availability of resources, all healthcare practitioners could introduce palliative care concepts and use already established resources to develop or improve their palliative care services. Healthcare systems must consider their mission and level of palliative care delivery (e.g., primary, secondary, tertiary) as they do other medical specialties, and they must incorporate a model of palliative care resourcing in accordance with that level.[19,20] Institutions with limited resources may choose a primary model that focuses on enhancing existing services and clinician education, while secondary and tertiary palliative care programs may provide multiple services, including inpatient and/or outpatient consult teams, an inpatient palliative care/hospice unit, and a home care program, all under the jurisdiction of a single hospital system. A full-service approach can ease transitions among different levels of care and has the potential to provide optimal, seamless palliative care. The CAPC also offers various consensus guidelines for operational and inpatient unit metrics that hospitals can use to measure programs for quality, sustainability, and growth.[9,20]

Primary Palliative Care

Primary palliative care should be available at all hospitals. This level of care requires, at a minimum, clinician education in the basics of pain and symptom management. Primary palliative care refers to a level of care whereby basic skills and competencies are required of all physicians, nurses, and other healthcare practitioners who encounter persons with life-limiting illness. The NCP, the National Quality Forum (NQF), and the Joint Commission have each identified standards that should be addressed in all hospitals and other settings (see later discussion). All practitioners should be competent at this level: they gain the knowledge, attitudes, and skills needed to provide palliative care to their patients through basic palliative care training and clinical practice. There is a growing availability of continuing education, including established formal programs for all disciplines to improve their knowledge of basic palliative care principles. The End-of-Life Nursing Education Consortium (ELNEC) and Education for Physicians on End-of-Life Care (EPEC) are two comprehensive educational programs that can provide such information. Both educational programs are further described in Chapter 72.

Secondary Palliative Care

Secondary palliative care refers to a model in which all providers have a minimum level of competence, and specialists provide palliative care through an IDT, specialized unit, or both. The development and success of these specialized services come about because of strong leadership, marketing, and accessibility.[18–20] It is not necessary for an IDT or unit to evaluate every patient with palliative care needs who is admitted to the hospital, but these specially trained clinicians are available as a resource and guide for their colleagues.

Tertiary Palliative Care

Teaching hospitals and academic centers with teams of experts in palliative care are classified as tertiary organizations. A tertiary-level program may serve as a consultant to primary- and secondary-level practices in difficult clinical situations or as model programs to assist developing centers. These centers also serve as training programs for incoming palliative medicine providers, with fellowship programs ranging from 1 to 2 years for both physicians and nurses. Practitioners and institutions involved at the tertiary level of palliative care are also involved in educational and research activities.[19,20] Multidisciplinary training programs for nurses and physicians are an important function of a tertiary center (see later discussion). Tertiary centers also have an obligation to perform research to enhance the evidence base for palliative care.

It is the responsibility of all hospitals and healthcare organizations to be competent, at a minimum, at the primary level of palliative care. Organizations at different levels may choose among different components of care to incorporate into their model. Some components are less resource-intense (e.g., staff education, care pathways), while others may require additional allocations of budget and personnel. The latter resources include IDTs, specialized PCUs, outpatient/ambulatory palliative care clinics, and structured outreach or strong relationships with skilled nursing facilities and home-based hospice programs.

The Inpatient Interdisciplinary Consult Team

A growing literature summarizes the development of palliative care consultation teams within hospitals to offer specialized consultation and expertise to patients, families, and other healthcare providers.[19] Many US and European hospital-based teams have described their experiences.[21–23] Among the components of successful teams are an interdisciplinary approach, physician and nonphysician referral, rapid response to requested consultations, around-the-clock availability, and ability to follow patients through all care settings.

Interdisciplinary consultation teams can be effective in modeling behaviors that are supportive of appropriate HBPC, but they should also recommend infrastructure and organizational changes as part of their approach to consultation. Gathering demographic statistics about the location and nature of regular consultations may help to identify the need for institutional policies and procedures. For example, if a unit or care provider has difficulty managing patients with dyspnea on a regular basis, targeted educational approaches and treatment algorithms or standardized orders may help achieve consistent and long-lasting change. Theoretically, an IDT could "put itself out of business" with such an approach. Conversely, teams may become "stretched too thin" in their attempts to meet the needs of their organization. However, the news remains positive: teams to date have not reported the need to dissolve as an outcome of implementing system changes.

Studies have begun to examine the impact of IDTs on the overall care of hospitalized, seriously ill patients.[24,25] However, this is challenging research, and, as in any multicomponent intervention, it is difficult to identify exactly which components or processes of the team are responsible for the outcomes. Valid, reliable measures and multimethod research are likely to be needed to capture this information.[24,25] Maintaining an IDT can be costly; therefore, it is imperative to continue to evaluate programs and strengthen the evidence base to provide economic justification for many hospitals.

A consensus panel has recommended minimum data that should be collected by all consultation services.[26,27]

Inpatient Hospice and Palliative Care Units

Some hospitals, faced with the problem of providing high-quality palliative care, have found the development of a specialized unit to be the solution. When access to palliative care is limited due to lack of availability or awareness,[17,21,25] hospitals in the United States have begun opening specialized units for the care of patients with hospice or palliative care needs (albeit with varying degrees of experience).[27–30] An inpatient unit has some advantages and disadvantages. Advantages include:

- Patients requiring palliative care have a familiar place to go during the exacerbations and remissions that come with progressive disease.[28–30]
- Unit staff and policies are under the control and financing of experts trained as a team who are skillful at difficult care and communications.[31,32]
- Patients may receive palliative care earlier if other care teams see the advantages of this approach and trust that patients will receive good care.[28–33]

Providers who monitor their patients on these units (if allowed) can learn valuable lessons about palliative care that can be carried forward to future patients.[33] These future patients may not require admission to the PCU for some types of care. Some disadvantages of creating a PCU include:

- It can prevent others from learning valuable palliative care techniques if the PCU staff are "specialized" and are secluded in one area.[34]
- Care providers may come to rely on this expertise instead of learning palliative care techniques themselves.
- If PCU transfer includes a transfer of doctors to a palliative care specialist, patients and families may feel abandoned by their primary team in the final hours.
- Hospice providers fear loss of the hospice philosophy when a PCU exists in the context of the general hospital.

Interdisciplinary Education: A Key Component of Palliative Care

It is imperative that staff caring for patients with life-limiting illness have sufficient and appropriate palliative care knowledge and skills. Organizations with or without HBPC programs should encourage staff members to participate in conferences on EOL and palliative care and should support them through the continuing education process (e.g., becoming certified in a specialty). The value of improved education is not only in direct patient care, but also in the role modeling that takes place. Most students in medical, nursing, and other healthcare disciplines receive clinical training for practice in hospitals.[35] However, few hospitals provide role models for teaching palliative care practices[35–37]; witness the following comments made by family members about the insensitive way that the act of "pronouncing" the death of their loved one was handled by an inexperienced new medical intern[37]:

> I was holding his hand when he stopped breathing. I called the nurse, who called the doctor. He went over and looked at him lying in the bed, listened for a heartbeat with his stethoscope, and said, "He's dead," and walked out of the room. That's it—not "I'm sorry." No, "Is there anything we can do?" Just, "He's dead." It was painful and made us think that the staff didn't care.

A study by Ferris and colleagues[36] documented that medical schools devote little time to care of dying patients. A survey of medical interns revealed significant concern and fear about providing these services with little or no supervision. The traditional "See one, do one, teach one" supervisory principle of medical education was ineffective. One resident explained that the pronouncing experience was not one that was perceived as causing harm when performed by inexperienced staff. Another stated, "I felt really inadequate, I had absolutely no idea what to do when the nurse called me to pronounce this patient whom I had never met—my first night on call. I was never taught the steps—how long should I listen to the chest to be sure there was no heartbeat; what, if anything else, I should do; what should I say to the family. Thankfully, the death coordinator was there to help me fill out the paperwork." Conversely, in states where nurses can pronounce deaths, some course work exists to teach a process that gives attention to the family. For resident education, there is a comprehensive, multimedia program called "The Art of Compassionate Death Notification."[38] The program includes a facilitator's guide, manuals for learners, a pocket card of the process, and videos demonstrating communication skills. At our medical center, the residency program conducts real-world patient scenarios where residents are given random patient case scenarios (actors play the role of patients/family) and carry out their evaluation of the case. These scenarios are observed by staff reviewers (physicians, nurse practitioners, ethicists) who then provide feedback to the resident regarding communication technique, body language, and more. The focus of such teaching formats is to provide trainees with honest feedback on their ability to navigate real-life scenarios and bring attention to both the areas in which they excel and those in which they need assistance or improvement, such as communication/choice of words, body language, and self-awareness.

The lack of role models for students in the clinical setting is further compounded by the lack of palliative care content in student curricula and major textbooks. When major medical and nursing texts were analyzed, they were found to be sorely lacking in content that would inform students about the basics of palliative symptom management, decision-making, and critical communication skills.[39–42] On a positive note, however, there is evidence that this situation is changing: the growing awareness of and need for palliative care has triggered greater incorporation of palliative care–focused content in medical and nursing school curricula and textbooks. Teaching formats have also become more innovative: Ellison and Radecke[43] conducted an "Issues at the End of Life" course as a joint effort between the office of a university chaplain and a palliative medicine program for college students. This course earned multiple teaching awards for originality, creativity, and collaboration. "Issues at the End of Life" divided the class into sessions focused on religious, spiritual, and theological issues and included guest presenters from Geisinger Medical Center in Danville, Pennsylvania, including physicians, nurses, bioethicists, hospice and social workers, and counselors. The objectives were to demystify aging, illness, and death while enhancing empathy and compassion to promote improved communication skills that could be used across various difficult situations. The most unique element of this course was its service-learning project for the creation of a personal legacy: each student worked with a designated community member facing EOL issues (due to advanced age, terminal illness, or both) to create a lasting, meaningful record of the person's life. Projects included audio- and video-recorded life histories, memory books, and even a memory quilt made from symbolic garments such as wedding attire, outfits from special occasions, baby blankets, and baptismal gowns. The course was a brilliant recognition of the common human experience of life and death—highlighting the need for better awareness, recognition, and interventions that offer as much attention at the end of life as one receives throughout life.

Creative Ways to Actively Engage Learners in Palliative Care Education

- Arrange for clinician role models to provide lectures to students and faculty.
- Assist with curriculum review of current EOL care training.
- Change elective coursework and clinical work in hospice and palliative care to required status and include these subjects in other mandatory clinical assignments.
- Use texts that contain clinically relevant palliative care content.
- Include content on ambulatory-based symptom management and decision-making that defines patient preferences for care.
- Encourage students to describe evidence-based approaches to palliative care and to challenge their mentors about approaches and interventions that increase the burden of care without clear patient benefit.
- Encourage students to learn from staff role models the appropriate ways of communicating bad news and presenting options that respect patient preferences and values.
- Identify opportunities for undergraduate or graduate fellowships in palliative care.
- Encourage quality improvement teams to offer students opportunities to participate and to collect data from patients, charts, and staff.

Experienced healthcare providers also have needs for specialty palliative care educational experiences (see Chapter 72). Both the nursing and medical professions have embraced the concept of palliative care continuing education, advanced academic training, and certification.

ELNEC and EPEC are exemplary continuing education programs. The ELNEC program is a collaboration of the City of Hope Medical Center and the American Association of Colleges of Nursing, and the program has a variety of curricula for different audiences (undergraduate and graduate nursing faculty, nurses working in critical care, pediatrics, or geriatric settings, etc.). The American Medical Association (AMA) and EPEC programs address similar issues for physicians. Both curricula are widely available to educate practicing nursing and medical staff.

The Harvard Medical School Program in Palliative Care Education and Practice

Another example of palliative care continuing education is sponsored by the Harvard Medical School Center for Palliative Care. In response to the need for leaders in palliative care education in nursing and medicine, the Harvard program offers intensive learning experiences for physician and nurse educators who wish to become expert in the clinical practice and teaching of comprehensive, interdisciplinary palliative care, as well as to gain expertise in leading and managing improvements in palliative care education and practice at their own institutions. The program includes a special pediatric track. The course is delivered in two sections: Part 1 consists of 7 days of intensive learning, followed by a 6-month interim when participants work on an individual project and contribute to weekly e-mail discussions of problematic clinical, educational, and program development cases presented by other participants through e-mail exchanges. Part 2 is a second 7-day block that includes continued experiential learning and training focused on communication, teaching methods, teamwork, and leadership.

The curriculum features content on how to (1) teach the fundamentals of palliative care (assessment of physical causes of distress, psychosocial and spiritual assessment, ethical and cultural issues, palliative care in geriatric and pediatric populations, depression, and bereavement); (2) communicate at the end of life (understanding the experience of life-threatening illness, delivering bad news, communicating across cultural barriers, family meetings, providing feedback to learners); (3) manage challenges in palliative care education (principles of adult learning, understanding, learning styles, new teaching methodologies); and (4) develop and promote clinical and educational programs in palliative care (assessing institutional structure and culture, evaluating readiness to change, dealing with resistance, developing and financing palliative care programs, and fund-raising strategies).

The course faculty includes physicians, nurses, social workers, and educators from within the Harvard teaching hospitals as well as outside experts. Complete information can be accessed at http://www.hms.harvard.edu/cdi/pallcare/pcep.htm

Advanced Education and Certification in Palliative Care

As standards of care are increasingly applied to HBPC programs, advanced specialty training in palliative care will likely become a requirement. Academic opportunities for education and preparation as an advanced palliative care practitioner currently exist in several programs (see Chapter 72). Following these programs and other specialized training, nurses may take advanced certification in palliative care through the National Board for Certification of Hospice and Palliative Nurses (NBCHPN). Eligible nurse practitioners and clinical nurse specialists can acquire credentialing as an Advanced Certified Hospice and Palliative Nurse (ACHPN). Certification exams are also available for registered nurses, licensed vocational nurses, nursing assistants, and nurse administrators. Nationally, hundreds of nurses have become board certified as palliative care specialists since this certification's inception.

A major advance in the field came about in 2007, when the American Board of Medical Specialties (ABMS) voted to approve hospice and palliative medicine as a recognized medical subspecialty. The application to recognize the subspecialty had broad support and was cosponsored by 10 medical specialty boards. As a result, physicians in many specialties—including internal medicine, family medicine, pediatrics, psychiatry, neurology, surgery, emergency medicine, and obstetrics and gynecology—can seek this certification. Prior to that time, this certification exam was offered by the American Board of Hospice and Palliative Medicine (ABHPM). In the first decade of certification, more than 2,100 physicians obtained certification from ABHPM. The ABHPM was not recognized by the ABMS, but worked successfully over the course of the decade to persuade the ABMS to recognize hospice and palliative medicine as a medical subspecialty. Although voluntary, this recognition is used by the government, healthcare systems, and insurers as evidence of high standards. There are currently 24 Member Boards of the ABMS (see www. abms.org). These 24 Member Boards constitute the officially recognized allopathic specialties of medicine in the United States.

Developing Standards for Hospital-Based Palliative Care

Several organizations have worked together to develop standardized palliative care practices.

National Consensus Project

In April 2004, the NCP for Palliative Care released its *Clinical Practice Guidelines for Quality Palliative Care*. An updated third edition of the guidelines was published in 2013, and the fourth edition in October 2018.[12] The guidelines, which can be downloaded free of charge from http://www.nationalconsensusproject.org, represent a consensus of four major US palliative care organizations: the American Academy of Hospice and Palliative Medicine, the CAPC, the Hospice and Palliative Nurses Association (HPNA), and the National Hospice and Palliative Care Organization (NHPCO). The guidelines identify core precepts and structures of clinical palliative care programs. The domains were intended as a framework for HBPC programs to develop and evaluate their approaches to delivering comprehensive palliative care services. Although voluntary, one potential outcome for these guidelines is to provide a framework for certification or mandatory accreditation.[12]

National Quality Forum

In 2007, in response to a need for national quality standards, the NQF released a document listing “preferred practices.” The NQF collaborated with the NCP in developing these 38 “best practices” or performance measures, which are organized under the NCP’s eight domains of care. The practices are evidence-based or endorsed by expert consensus and apply to hospice and palliative care services across all care settings.

The NQF is a nonprofit, public–private partnership organization whose mission is to develop ways to improve the quality of US healthcare. The NQF has representation from national, state, regional, and local organizations representing consumers, public and private insurers, employers, professionals, health plans, accrediting bodies, labor unions, and other organizations representing healthcare research and quality improvement. They rely on or use consensus-building processes to develop national standards for the measurement and public reporting of healthcare performance that is safe, timely, beneficial, patient-centered, equitable, and efficient. These standards have served in other areas of care as a method to link performance with reimbursement.

Center to Advance Palliative Care

One of the major efforts to improve HBPC programs in the United States is led by the CAPC. Originally formed and funded by a 4-year grant from the Robert Wood Johnson Foundation in 2000, the national center was established at Mount Sinai School of Medicine in New York City. The Center has a mission to make available to hospitals and health systems nationwide information on how to establish high-quality palliative care services.

The CAPC assists hospitals with the planning, development, and implementation of HBPC programs. In addition to assisting hospitals and other health systems in program development, CAPC facilitates collaboration among hospitals, hospices, and nursing homes; promotes educational initiatives in palliative care; and encourages growth and development of new and innovative mechanisms for financing palliative care programs.[20,44,45] More recently, the CAPC has collaborated on the development of a strong evidence base and palliative care research with the National Palliative Care Research Center (NPCRC, described later in this chapter).

The CAPC has developed palliative care leadership centers (PCLCs) to assist organizations that wish to learn the practical aspects of developing a palliative care program.[44] Among the PCLCs are Fairview Health Services, Minneapolis, Minnesota; Massey Cancer Center of Virginia Commonwealth University Medical Center, Richmond; Medical College of Wisconsin, Milwaukee; Mount Carmel Health System, Columbus, Ohio; Palliative Care Center of the Bluegrass, Lexington, Kentucky; and University of California, San Francisco. Each represents a different type of healthcare system and palliative care delivery model. They serve as exemplary organizations offering site visits, hands-on training, and technical assistance to support development of palliative care programs nationwide. Further information regarding the PCLCs can be found on the CAPC website (http://www.capc.org).

The National Palliative Care Research Center

The mission of the NPCRC is to improve care for patients with serious illness and address the needs of their families by promoting palliative care research. In partnership with the CAPC, the NPCRC aims to rapidly translate these findings into clinical practice. The NPCRC uses three mechanisms to accomplish its aims:

- Establish priorities for palliative care research;
- Develop a new generation of researchers in palliative care;
- Coordinate and support studies focused on improving care for patients and families living with serious illness.

The NPCRC, located in New York City, receives direction and technical assistance from the Mount Sinai School of Medicine. Prior to the establishment of the NPCRC, there was no organizing force promoting and facilitating the conduct of palliative care research. Because departments or divisions of palliative medicine do not yet exist in most medical schools, palliative care research is conducted by a small number of highly successful investigators working in isolation at a limited number of universities and clinical settings in the United States.

The NPCRC provides an administrative home to promote intellectual exchange, sharing of resources (e.g., biostatisticians), and access to data from ongoing studies to plan and support new research. Furthermore, the Center takes a collaborative approach to establishing its funding priorities. It is a key force in the development of an evidence base from which standards of HBPC can be developed and measured. (For more information about its activities, see http://www.npcrc.org.)

The Joint Commission

The Joint Commission is one of the paramount accreditation organizations for hospitals and other healthcare organizations. Its purpose is to continuously improve the safety and quality of care provided to the public. The Joint Commission is an independent, not-for-profit organization, and perhaps its most important benefit is that Commission-accredited organizations make a commitment to continuous improvement in patient care. During an accreditation survey, the Joint Commission evaluates a group's performance by using a set of standards that cross eight functional areas: (1) rights, responsibilities, and ethics; (2) continuum of care; (3) education and communication; (4) health promotion and disease prevention; (5) leadership; (6) management of human resources; (7) management of information; and (8) improving network performance.[46,47]

In 2004, a specific palliative care focus was introduced within two standards: (1) rights, responsibilities, and ethics and (2) the provision of care, treatment, and services. The goal of the first standard is to improve outcomes by recognizing and respecting the rights of each patient and by working in an ethical manner. Care, treatment, and services are to be provided in ways that respect the person and foster dignity. The performance standard states that a patient's family should be involved in the care, treatment, and services, if the patient desires. Care, treatment, and services are provided through ongoing assessments of care; meeting the patient's needs; and either successfully discharging the patient or providing referral or transfer of the patient for continuing care. Institutions and providers are encouraged to seek and maintain advanced certification in palliative care delivery.[47] More detailed information is available by contacting the Joint Commission or visiting their website at http://www.jcrinc.com.

These standards incorporate a stronger emphasis on palliative care practices within organizations. Hence, organizations are being held accountable for the way they provide appropriate palliative care. It is in the public's best interest that the Commission requires organizations to adhere to these provisions for a successful accreditation. In 2008, a process to develop specific "Certification for Palliative Care Programs" was begun, and, in 2011, the Commission's Advanced Certification Program for Palliative Care[47] was launched: the standards for palliative care certification are built on the NCP's *Clinical Practice Guidelines for Quality Palliative Care* and the NQF's *National Framework and Preferred Practices for Palliative and Hospice Care Quality*. Standards and expectations were developed using experts in palliative care and key stakeholder organizations. The standards are published in the *Palliative Care Certification Manual*.

Chapters address the following issues:

- Program management
- Provision of care, treatment, and services
- Information management
- Performance improvement

To be eligible for Advanced Certification for Palliative Care, a palliative care program must:

- Be provided within a Joint Commission-accredited hospital. All types of hospitals are eligible, including children's hospitals and long-term and acute care hospitals. A dedicated unit or dedicated beds are not required.
- Provide the full range of palliative care services to hospitalized patients 24 hours per day, 7 days per week:
  - Programs must have team members available to answer phone calls nights/weekend and the ability to come to the hospital to see patients 24/7 when necessary to meet patient/family needs.
  - Programs must be able to provide the same level of palliative care services during nights/weekends as during normal weekday hours.
  - Programs are not required to have palliative care team members physically present in the hospital 24/7.
- Have served a minimum of 10 patients and have at least one active patient at the time of the initial Joint Commission on-site review. Hospice patients are eligible for inclusion in the minimum patient count only if they were receiving inpatient palliative care from the program prior to transitioning to hospice care. These patients may be selected for tracer activity during the on-site review, with the reviewer focusing on the episode of inpatient palliative care closest to the hospice transition.
- Use a standardized method of delivering clinical care based on clinical practice guidelines and/or evidence-based practice.
- Direct and coordinate the provision of palliative care, treatment, and services for the program patients (that is, write orders, direct or coordinate activities of the patient care team, and influence composition of the patient care team).
- Follow an organized approach supported by an IDT of health professionals.
- As of January 2017, all hospitals currently certified in the Advanced Palliative Care program, as well as those hospitals seeking initial certification, will be required to implement data collection for five standardized measures effective with discharges on and after January 1, 2017.
- Updates on the Joint Commission progress on standard development can be obtained from the Commission's website under "certification programs": http://www.jointcommission.org/certification/palliative_care.aspx.

Veterans' Health Administration Initiatives

Please see Chapter 44 for more information.

Professional Societies Contribute to Palliative Care Development

Multiple professional societies have made contributions to the development of HBPC generalized or specialty population-specific palliative care standards, guidelines, or consensus statements by raising professional and public awareness of the unique issues of palliative care. A few selected organizations and their initiatives are described in this section.

National Hospice and Palliative Care Organization

The NHPCO was founded in 1978 as the National Hospice Organization. The organization changed its name in February 2000 to include palliative care. Many hospice care programs have added palliative care to their names to reflect the range of care and services they provide because hospice and palliative care share the same core values and philosophies. According to its website, the NHPCO is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The NHPCO is committed to improving EOL care and expanding access to hospice care with the goal of profoundly enhancing QOL in America for the dying and their loved ones. The NHPCO advocates for the terminally ill and their families. It also develops public and professional educational programs and materials to enhance understanding and availability of hospice and palliative care, convenes frequent meetings and symposia on emerging issues, provides technical informational resources to its membership, conducts research, monitors congressional and regulatory activities, and works closely with other organizations that share an interest in EOL care.

Hospice and Palliative Nurses Association

The HPNA was incorporated in 1987 to establish a network and support for nurses in this specialty. In 1998, the organization formally added palliative care to its mission to recognize the needs of nurses working in palliative care settings separate from hospice. The HPNA has become the nationally recognized organization providing resources and support for advanced practice nurses, registered nurses, licensed practical nurses, and nursing assistants who care for people with life-limiting and terminal illness. To guide best practices, they have developed numerous position statements and standards that are available to members and nonmembers on a variety of topics.

Processes for Providing HBPC

While HBPC programs are increasing in number, many organizations are still at the stage of contemplating enhancing palliative resources or developing a program. Such an endeavor requires careful planning, as these programs are not "one size fits all." Patience, persistence, and consensus-building are vital to successful program development. As described earlier, the CAPC has taken a leadership role in assisting organizations of all types to build a successful program that is suited to their unique patient population, resources, and organizational culture.

Process of HBPC Program Development

Regardless of organizational type, the first step in developing a HBPC program is to perform a system assessment or "organizational scan" to identify existing organizational strengths, resources, potential partnerships, and collaborators.[5] A task force or team of interested clinicians, administrators, and possibly consumers might be a good start. Examples of possible existing resources include clinicians from all disciplines with interest and training in palliative care, existing relationships with hospice, case management, discharge planners, and hospital chaplaincy programs. The needs assessment should determine the hospital focus on length of stay, ventilator days and pharmacy/ancillary costs per day, palliative care leadership based on personal experience or professional interest, preexisting pain programs, and trustee/philanthropic interest in and support for palliative care. After the system assessment is performed, the second step is to identify areas of need within the organization to highlight where palliative care programs can make the greatest contribution. Many institutions have easy access to data that can help to "build the case" for palliative care. Selling the idea of palliative care to an institution or gaining institutional support is easier when benefits (such as cost savings, efficiency, and improved clinical care) can be shown. Common areas of need that have shown improvement because of HBPC programs include pain and symptom management, patient and family satisfaction, nurse retention and satisfaction, bed and intensive care unit (ICU) capacity, and length of stay. Other outcomes may include pharmacy costs, establishment and strengthening of hospice partnerships, and improving fragmented subspecialty care. To assist organizations with the complexities of the planning process, the CAPC provides a systems assessment tool and a needs assessment checklist, which can be found at https://www.capc.org/search/?q=system+assessment+tool.

The Process of Providing Palliative Care: Developing an Interdisciplinary Team

The holistic process of providing palliative care to patients and their families is rarely accomplished by one individual or discipline. The IDT is the foundation of the HBPC service and is uniquely different from the traditional delivery of medical care. The core IDT typically consists of specially trained palliative care professionals, including physicians, nurses at all levels of training (registered nurses, nursing assistants, and advanced practice registered nurses [APRNs]), social workers, pharmacists, spiritual care counselors, healing arts/complementary practitioners, hospice representatives, and volunteers.[60]

Identifying which team member(s) can best serve a patient's needs is a key part of the initial assessment. One clinician may be designated to receive initial consults and organize distribution of work for the day. A team may decide that all new consults are seen first by a medical provider: either the physician or the APRN. The physician also serves as the medical resource person for other team members and supervises physician learners. APRNs may work independently or collaboratively with the attending physician to conduct initial consultations. If resources allow, this may be done together; however, workload and resources may dictate that new consults are divided among the medical providers. In organizations that support learners, after a period of supervision and observation, it may be that the learner (e.g., fellow, resident, medical or nursing student) conducts an initial chart review and patient and/or family interview and then presents the patient to the physician or APRN, after which the pair will revisit the patient. At all times the team should be aware of the patient's energy level and the learner's level of expertise in deciding whether this format is appropriate. During the initial consult psycho/social/spiritual needs are identified and other team members are integrated into the plan of care.

A palliative care–certified physician and/or APRN may be responsible for the initial assessment and day-to-day medical care of most patients. However, depending on the patient's needs, another member of the team might take the lead in care. For example, if the patient's primary concern is physical, then a medical provider may direct the plan of care. If the patient's primary concern is existential in nature, the spiritual care provider may take the lead. Alternatively, if the patient's primary need is for family support, the social worker may be the most active care provider. Healing arts and complementary medicine practitioners and volunteers are also integral members of the IDT. Healing arts/complementary medicine practitioners are providers from a variety of backgrounds who can provide massage, energy work, or instruction in guided imagery or meditation. Palliative care volunteers are specifically trained to see palliative care patients and are overseen by a volunteer coordinator. They provide presence, active listening, and company for patients and families. Although some tasks are seemingly small, such as reading, playing cards, or running small errands, these are often essential aspects of care from the patient/family perspective. Pharmacists, healing arts/complementary therapy clinicians, hospice liaisons, and volunteers may or may not be part of the core team in some organizations. For example, even though medication needs may be complex, few teams have a dedicated pharmacist who can round daily with the team. Hence, it may be more realistic to have a pharmacist present during regularly scheduled IDT meetings. Similarly, local hospice liaisons, healing arts/complementary therapy practitioners, and others may only be available to meet with a team weekly. Nonclinical members of the team including administrative, financial, or practice managers and secretarial support are responsible for holding the IDT together by providing the supportive infrastructure within which the team can operate. These key team members may serve as representatives or liaisons on important institutional committees. Another important function of program administrators is the collection of data for clinical and fiscal evaluation for quality improvement, program justification to the institution, or research. The receptionist/secretarial support may be the first contact for patients and referring clinicians and can become the "face or voice of the program." Individuals selected for these positions should be skilled, patient, and caring to enable them to deal with the stress of people in crisis and the urgency of consultations. After an initial consultation, depending on the patients' needs, they may continue to be seen in follow-up throughout their hospitalization. Some patients may have acute needs (such as uncontrolled pain) that may require them to be seen more than once daily. Other patients may be seen several times a week or weekly or until the goal of the initial consultation is achieved. Some patients may be visited by the medical provider, the spiritual care provider, the healing arts provider, and a volunteer—all on the same day.

Processes to Support Interdisciplinary Team Communication

Communication may be the most challenging and crucial aspect of providing palliative care.[48–50] Intrateam communications that are regular and efficient will allow for seamless care to be delivered. Teams will likely explore a variety of mechanisms to achieve optimal communication about not only issues of patient care but also team function.[50] The purpose of regular patient care–related team meetings is to allow all disciplines to contribute to the development and implementation of comprehensive care plans that reflect the values, preferences, goals, and needs of each individual patient.[49] Practicing as a true IDT requires significant and ongoing intention and effort. Traditionally, the medical model has driven healthcare delivery and, to a large extent, still does. However, in a holistic care model of palliative care, the psycho/social/spiritual care providers should have equal authority and input; for many clinicians, this represents a change in practice. Teams should be mindful of tendencies to become "efficient" that can sometimes lead to a focus only on the medical or physical aspects of care. Minimally, a weekly face-to-face meeting in which all IDT members gather is considered an essential element of team function to provide high-quality, coordinated care. During the IDT meeting, active patients are presented, and all team members have an opportunity to contribute their expertise in the development of the plan of care.

Performing the Palliative Care Consult

A palliative care consult can be initiated in a variety of different ways. Some services (or reimbursement mechanisms) require that a physician initiate the consult, rather than a nurse or other care provider. If someone other than the attending physician requests a consult on a hospitalized patient, it is important to include the attending (or primary care) physician in the consult. Ideally, a provider-to-provider conversation prior to consultation would review and identify the priority issues. Most services do this before seeing the patient.

When Is a Consult Made?

Consultations should be initiated at any time a person with a life-limiting illness has physical, psychological, social, or spiritual needs.[26,32,51] Palliative care programs began for many reasons, but one of them was to meet the EOL care planning and symptomatic needs of patients who are not yet hospice-eligible, either because of life expectancy (greater than 6 months) or because they are receiving active, disease-modifying treatment. Palliative care referrals do not hinge on the "less than 6 months" life expectancy, as is often the case for hospice referrals. Referring patients with life-limiting illness early is one of the benefits of having a palliative care service. Some organizations have built-in consult triggers, protocols, or algorithms for specific life-limiting illnesses in which consults are recommended at diagnosis. "Automatic referrals" would be generated for all patients who are newly diagnosed with certain types of life-limiting cancers (e.g., pancreatic, brain, stage IIIB and greater lung, liver, etc.), or teams may simply rely on the utility of the "surprise" question,[54] a validated research tool commonly used in palliative care research to help identify those patients at higher risk for 1 year mortality and who would therefore likely benefit from palliative care. Figure 3.1 provides an example of a "trigger tool"; this tool was piloted in various settings, including the adult ICU, inpatient oncology, and general medical surgical floors. Noncancer patient populations that may be considered for automatic referrals are those with amyotrophic lateral sclerosis (ALS), heart failure, end-stage dialysis-dependent renal failure, and those who, regardless of diagnosis, experience frequent hospitalizations. These patient populations are typically highly in need of palliative care services. Careful planning and close collaboration with colleagues are necessary to establish a process for automatic referrals that ensures that those patients who are most in need of palliative care services have them "early and often." Some automatically scheduled palliative care consultations may occur in the outpatient setting or clinic, while some organizations have hospital "triggers" that may alert that primary team that a patient may benefit from these specialized services. Over time, in HBPC programs with high community visibility and/or marketing efforts, it may be common to have patients or family members self-refer.

What Is Included in the Initial Palliative Care Consultation?

The initial consult will lay the foundation for all further interactions with the patient and family. In addition to specialty expertise, the palliative care team may offer the unique resources of presence and time. Much has been written about the importance of sitting during the initial consult. Making sure there is adequate time to see the patient and family is crucial.[52] If time restrictions are unavoidable, state these constraints at the outset of the consultation. Sitting

PALLIATIVE AND SUPPORTIVE MEDICINE CONSULT TOOL
(Worksheet only. Not part of permanent medical record.)

Medical Record Number: _______________ **Age:** ___________ **Reason for Admission:** _____________________

To evaluate appropriateness of a PSMC, consider the following criteria:

		SCORING
1) ***Would you be surprised if this patient were alive in one year?***		
Yes – Score 3 points		
No – Score 0		
	TOTAL SECTION 1 (0 OR 3)	

2) ***Basic Disease Process***	Score 2 points each	
a. Cancer (metastatic/recurrent)		
b. Advanced COPD (requires home oxygen)		
c. Neurological disease (difficulty swallowing or incontinent)		
d. End stage renal disease (considering stopping dialysis)		
e. Advanced congestive heart failure (one-block DOE)		
f. >3 hospitalizations or ED visits for incurable disease in past year		
g. Other terminal or incurable disease causing significant symptoms		
TOTAL SECTION 2		

3) ***Uncontrollable Symptoms or Clinical Conditions***

Score 2 points each		Score 1 point each		Score 1 point each		
a. Pain		e. Anxiety		i. Prolonged vent support		
b. Dyspnea		f. Depression		j. Other _____________		
c. Nausea		g. Weight loss				
d. Bowel obstruction		h. Constipation				
				TOTAL SECTION 3		

4) ***Anticipated Functional Status of Patient at Time of Discharge*** Score as specified

Using ECOG Performance Status (Eastern Cooperative Oncology Group)

Grade	Scale	Score	
0–1	Fully active, able to carry on all pre-disease activities without restriction or restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature.	0	
2	Ambulatory and capable of most self-care but unable to carry out any work activities. Up and about more than 50% of waking hours.	1	
3–4	Capable of only limited self care; confined to bed or chair more than 50% of waking hours or worse.	3	
		TOTAL SECTION 4 (0, 1, OR 3)	

5) ***Psychosocial issues (patient or family)***	Score 2 points each	
a. Need to discuss end of life issues		
b. Need for evaluation for possible hospice referral		
c. Artificial hydration or nutrition requested or considered		
d. Unrealistic goals or expectations		
TOTAL SECTION 5		
TOTAL SCORE SECTIONS 1–5		

SCORING GUIDELINES:

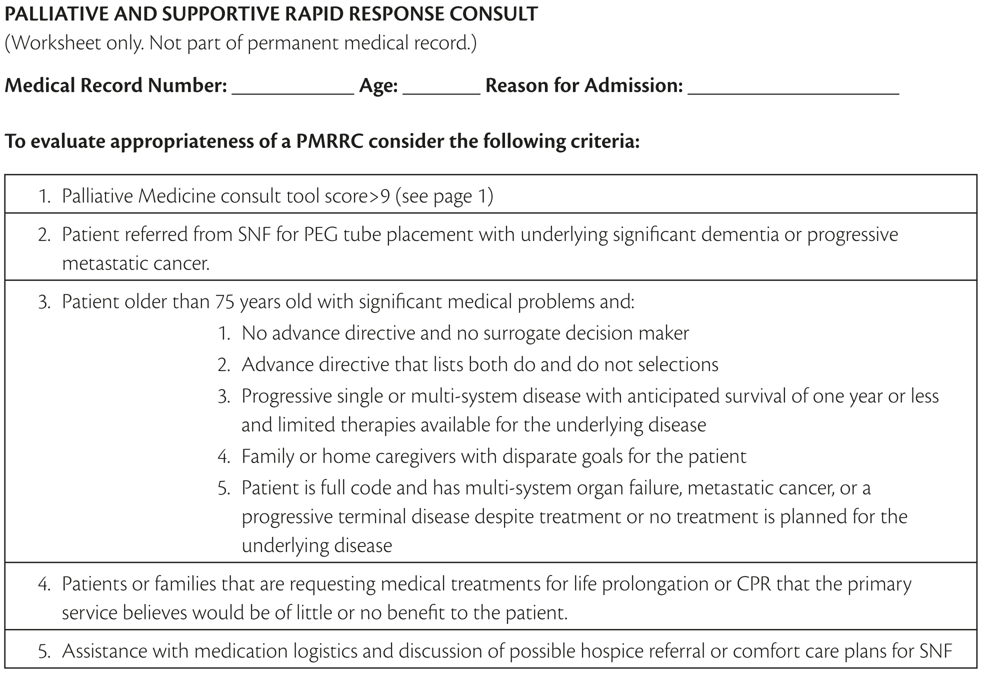
TOTAL SCORE ≤ 8	Problem-directed consult, if desired
TOTAL SCORE = 9–11	Consider PSMC
TOTAL SCORE ≥ 12	Strongly consider PSMC

Form completed by: ____

Date: _______________________

Figure 3.1 Geisinger Medical Center Palliative and Supportive medicine consult tool and palliative and supportive rapid response consult tool.

Source: Developed by Neil Ellison, MD, and Patricia Maani-Fogelman, DNP, Geisinger Health System.



PALLIATIVE AND SUPPORTIVE RAPID RESPONSE CONSULT
(Worksheet only. Not part of permanent medical record.)

Medical Record Number: ___________ **Age:** _______ **Reason for Admission:** ____________________

To evaluate appropriateness of a PMRRC consider the following criteria:

1. Palliative Medicine consult tool score>9 (see page 1)
2. Patient referred from SNF for PEG tube placement with underlying significant dementia or progressive metastatic cancer.
3. Patient older than 75 years old with significant medical problems and: 1. No advance directive and no surrogate decision maker 2. Advance directive that lists both do and do not selections 3. Progressive single or multi-system disease with anticipated survival of one year or less and limited therapies available for the underlying disease 4. Family or home caregivers with disparate goals for the patient 5. Patient is full code and has multi-system organ failure, metastatic cancer, or a progressive terminal disease despite treatment or no treatment is planned for the underlying disease
4. Patients or families that are requesting medical treatments for life prolongation or CPR that the primary service believes would be of little or no benefit to the patient.
5. Assistance with medication logistics and discussion of possible hospice referral or comfort care plans for SNF

Figure 3.1 Continued

down during the consultation and making sure everyone who is participating in the consult has a seat is important (see Chapter 5, "Communication in Palliative Care"). Depending on the resources available and the composition of the team, an initial consult can occur almost anywhere. For inpatient consults, it is often in the patient's room; for outpatient consults, it may be in the clinic exam room. If resources permit, consults can also be done at the patient's home or in local care facilities. The main concern is an environment that allows for privacy and quiet—often difficult to find in most acute care hospitals.

Patients are generally unfamiliar with the term "palliative care" and/or associate it with hospice care or death. Patients who are early in their disease process may wonder why a consult to this service has been initiated. Establishing the patient's level of understanding and explaining the role and focus of the palliative care team is an important starting point to the consultation. Often patients and families may need reassurance that they are not being "abandoned" by their primary team. Explaining that the palliative care team consults and provides expert guidance to the primary team but does not replace them is important. Providing a clear and confident explanation of services will help everyone know what to expect. Providing a brochure or some written information about what palliative care is and who the team members are can be helpful. Assessing patient/family knowledge and understanding their current situation is the next step. Healthcare providers often believe that they have done a complete and thorough job in explanations; however, patients are under stress and may need multiple explanations in very simple language before they fully understand their situation.[50,52] Next, a complete and thorough assessment is begun. This should include a review of symptoms and physical complaints as well as an assessment of psychological, emotional, social, and spiritual concerns. Eliciting a clear picture of the patient's social support structure and family relationships is essential as the contextual issues will often affect, if not drive, decision-making. Exploring what gives meaning to patients' lives and who they are as individuals will help direct care. Do not hesitate to humanize the medical encounter by taking the time to get to know the patient as an individual—their hobbies, passions in life, the meaning they attribute to work and family are all important aspects of learning about a new individual. Assessing and attending to cultural preferences will enhance communication and increase the effectiveness of interventions.

Other areas that are important to assess are goals of care, advance care planning wishes, and treatment decision-making style. Due to time constraints and sometimes lack of skill, these complex issues are often overlooked or only superficially explored by the primary team. Yet they are some of the most important pieces of the puzzle when constructing a plan of care. It is important to find out what the patient/family is hoping for from treatment interventions. This is where the role of nursing advocacy comes in: as the individuals spending the greatest amount of time at the bedside, nurses can often identify patient/family personal preferences and goals, ascertaining the answers to questions such as "What does getting better mean to you?" Often, this issue is ignored when, in fact, it needs more time and consideration. To the medical team, "getting better" may mean the patient is able to leave the hospital; to the patient, it may mean a full recovery or expectation of return to a higher level of functionality. The clinical implications of a new disease or advanced illness are not always clear to the patient or family, requiring further review and discussion. Exploring, on the first visit, whether the patient and family have ever considered and/or completed advance directives may elucidate this. Completing advance directives is a structured way of looking at goals of care and what is meaningful when making treatment decisions. Some programs have developed standardized templates that remind the team (and the referring provider) of the important and comprehensive domains of care and intervention that are included in the consultation.

Who Should Be Present at an Initial Consultation?

While there are times when it is appropriate to conduct a consult without the patient present (e.g., the patient is in a coma), in most cases, every effort is made to include the patient. The patient should decide which support members and/or family he or she wants to include. There may be one or more members of the palliative care team present. A member from the referring team may want to attend, but this is less common on initial consult. If a focused family meeting is arranged, it is imperative that the referring team be present, so all decision-makers are in the room together. Family meetings are a large part of palliative care interventions.[50,52] During the initial consult it may be clear that a family meeting is needed to proceed with discussion about care planning, and, on occasion, such a meeting may be simultaneously organized as a part of the initial consult. Direct inquiry with the patient will also identify key family/support members desired for any discussions, and efforts should be undertaken to include those identified whenever possible. Conducting a family meeting takes skill and planning—in today's hectic world, it is often difficult to coordinate multiple schedules or for family members to reach the hospital due to distance and other concerns. In these instances, the use of teleconferencing[53,54] has become especially helpful. Resources are available to assist inexperienced team members with the important process of organizing and conducting a family meeting.

Continuing the Care: Day-to-Day Operations

Patients with serious illness may follow many different paths: they may be typical in the current "care as usual" for a seriously ill patient compared with an "ideal" or expected pathway in a healthcare system with an HBPC program. Numerous institutions have studied their processes of care and have created clinical pathways that can help standardize procedures and reduce the variation of care experienced by terminally ill or symptomatic palliative care patients as they traverse the complex healthcare system. Usual components include attention to patient symptoms as well as family needs at system entry and throughout the course of stay until discharge. Assigning time frames to address needs helps in monitoring progress and tracking outcomes that have been met, as well as those that continue to need attention. Although published guidelines and standards may offer similar suggestions, the road map format of clinical pathways identifies practical and accountable mechanisms to keep patient care moving in the direction of specific identified outcomes. Some pathway forms allow for documentation of variation from the designated path. Analysis of several instances of variation might alert a care team about a potential system "defect" in need of improvement.

Many institutions have implemented standard orders or evidence-based algorithms to guide various aspects of care pertinent to EOL situations. Some of these include limitations of certain types of therapies such as cardiopulmonary resuscitation (CPR) and blood pressure medications. In addition, preprinted order sheets that outline management of symptoms and side effects such as nausea, constipation, and pain are making it easier for physicians and trainees to reproduce comprehensive plans that do not vary because of individual opinion. These order forms can be valuable teaching tools in a setting of regularly changing care providers. Nurses can advocate through development of hospital policy, education, and individual practice for aggressive comfort care. The healthcare team must ensure that a positive approach—focusing on what can be done for patients with life-limiting illness and their families—is implemented. At a macro level of cancer care, the National Comprehensive Cancer Network[55] has published detailed "care standards" in its *Palliative Care Clinical Guideline*. This booklet is produced as a professional and patient guide and is available from http://nccn.org.

Documenting Palliative Care Consultations

As in all aspects of healthcare delivery, documentation is the foundation for communicating with other providers, particularly across care settings. As a consultative service, including the primary care providers, the plan of care promotes collegiality and helps assure follow-through. Recommendations for symptom management; identification of goals of care, advanced illness planning, and resuscitation wishes; or emotional counseling and support are at the heart of the palliative care assessment and interventions. An electronic medical record (EMR) may provide an immediate way to share information with all members of the care team. Pertinent members with whom the consult should be shared include the primary referral service (if the patient is inpatient), the primary care provider, and other specialties consulting on the patient. Providing a copy of the consultation note, electronically in real time, can assist with the timely communication and implementation of recommendations.

Documentation can also be a vehicle for education that should not be overlooked. Including specifics in the plan of care can help other providers learn aspects of palliative care. For example, breakthrough dosing for pain medications is often underdosed by the primary team. When addressing pain management in the palliative plan of care, noting the total daily opioid use and writing the details of the calculation (10–20% of total daily need) in print can teach other providers how to prescribe adequate breakthrough medication in the future. Clear and concise communication helps every member of the team.

Finally, documenting goals of care, resuscitation wishes, and advance care planning in a way that is visible to everyone is a challenge. Patients often complain that they have provided documents or information, such as an advance directive, but, at the point of care, the information is not easily located. As a quality improvement initiative, our institution created a visible tab embedded in the EMR for advance directives. In this system, important documents (advance directives and Do Not Resuscitate orders) are scanned into the record and are readily available. This decision is also added to the patient's EMR-based problem list so that every provider accessing the chart can quickly determine if the patient has, for example, elected no code status, completed an advance directive, and the like. For patients who have verbally stated wishes but have not completed the official document, a clinician can complete a templated advance care planning note that carries the same force as an official form. This can be completed by any team member and can indicate the durable power of attorney as well as care wishes (resuscitation wishes, medically administered nutrition/hydration wishes, etc.). The templated notes and actual documents are all located in the same section of the EMR and are accessible to all providers (including in the Emergency Department and physician offices that are part of the medical center system).

Completing the Process: Transitions of Care and Continuity

The palliative care team must remember that they are the consultants and that, ultimately, most patients will remain under the guidance of the primary provider. While some referring providers welcome aggressive assistance in care, others may prefer to accept or decline palliative care team recommendations. Talking a case over with the primary team is always preferable to leaving a note in the record. Continuity is improved dramatically when there is an outpatient as well as an inpatient component of an HBPC.

For patients who do not return to the center, providing continuity is difficult. Sending the initial palliative care consult and pertinent notes to the receiving team (including the patient's primary care provider or skilled nursing facility, if applicable) is useful. Being open to phone calls or proactively placing a personal call to the receiving provider will help to build bridges to the community and encourage community providers to see the palliative care team as a resource.

Outcomes and Their Measurement: The Role of Quality Improvement and Research in Hospital-Based Palliative Care

Measurement of outcomes is vital to demonstrate quality and to maintain viability and growth of HBPC programs. Although the field is still developing, tools are beginning to emerge to measure care, assist with developing standards of care, and, most importantly, bring individual and organizational transparency and accountability to the care that is being delivered. Documentation of less than excellent outcomes may result in the organizational tension needed for change to occur. Such motivation can stimulate improvement and motivation for both administrators and clinicians.

As described earlier in this chapter, several organizations such as the CAPC, NQF, and NCP have urged all programs to collect standardized measures across settings. The CAPC has taken the lead in providing technical assistance in this regard. Resources for business, clinical, quality management, and strategic and financial planning are available on the CAPC website, with a link to the actual tools and instruments for measurement and planning of clinical care.

Several efforts have been initiated to advance the measurement of palliative care outcomes. In 2014, the Institute of Medicine (IOM) published *Dying in America*; the IOM committee believes a person-centered, family-oriented approach that honors individual preferences and promotes QOL through the end of life should be a national priority. *Dying in America* provides a comprehensive assessment of the knowledge gaps, structural problems, and financial disincentives that hamper delivery of optimal care, and it makes cross-sectoral recommendations to achieve compassionate, affordable, sustainable, and effective care for all Americans.

The American Society of Clinical Oncologists (ASCO), recognizing that oncologists had few reliable resources to assess and measure the quality of supportive care delivered in their practices, launched a health plan program developed by its Quality Oncology Practice Initiative (QOPI). Data are collected on a quarterly basis and, if desired, reported by ASCO to insurers. Measurement of data in this fashion not only impacts the quality of care delivered within an individual program but also promotes evidence-based practices and standardization across settings. In 2016, ASCO updated the "Integration of Palliative Care into Standard Oncology Care," a document which provides evidence-based recommendations to oncology clinicians, patients, family and friend caregivers, and palliative care specialists and is designed to update the 2012 ASCO provisional clinical opinion (PCO) on the integration of palliative care into standard oncology care for all patients diagnosed with cancer. This update is the most current evidence-based guideline, using nine randomized controlled trials (RCTs), one quasi-experimental trial, and five secondary analyses from RCTs in the 2012 PCO. In the 2016 update, ASCO recommended that inpatients and outpatients with advanced cancer should receive dedicated palliative care services early in their disease trajectory and that it should be concurrent with active treatment.[48] Details can be viewed directly at www.asco.org/palliative-care-guideline.

The CAPC website and a printed technical manual contain tools for measuring HBPC outcomes. When assisting an organization to establish a program, CAPC encourages the incorporation of clinical, financial, operational, and customer metrics.[27]

The CAPC convened a consensus panel to discuss which operational metrics should be measured as programs "strive for quality, sustainability and growth" and which metrics can be used to "compare service utilization across settings." The 12 domains of operational data that were agreed on may be used to compare service characteristics and impact within a program or between programs. The four categories of measurement to assure effectiveness and efficiency recommended by CAPC are (1) clinical (pain and symptom control) metrics, (2) program operational measures, (3) customer metrics (satisfaction surveys of patients, families, and providers), and (4) financial metrics (Table 3.1). Examples of actual tools to measure these characteristics are available on the CAPC website mentioned earlier.

Every program should have a plan to measure and monitor its effect on the quality of patient care, ideally from program inception. Some measures will be useful for internal planning for staffing, need for program growth, and productivity goals. These same measures could then be compared to other programs as external benchmarks, especially for newer programs under development. Ultimately, the data collected can be used to assure that high-quality palliative care is provided across organizations.[20,27] CAPC also collates national data on the prevalence of HBPC teams, which can be further evaluated by state at https://reportcard.capc.org/tables-charts/ (see Figure 3.2).

Table 3.1 Metric categories

Metric domain	Examples
Operational	Patient demographics (diagnosis, age, gender, ethnicity) referring clinician, disposition, hospital length of stay
Clinical	Symptom scores, psychosocial symptom assessment
Customer (patient, family, referring clinicians)	Patient, family, referring clinician satisfaction surveys
Financial	Costs (pre- and post-HBPC consultation), inpatient palliative unit, net loss/gain for inpatient deaths

Source: Reference 30.

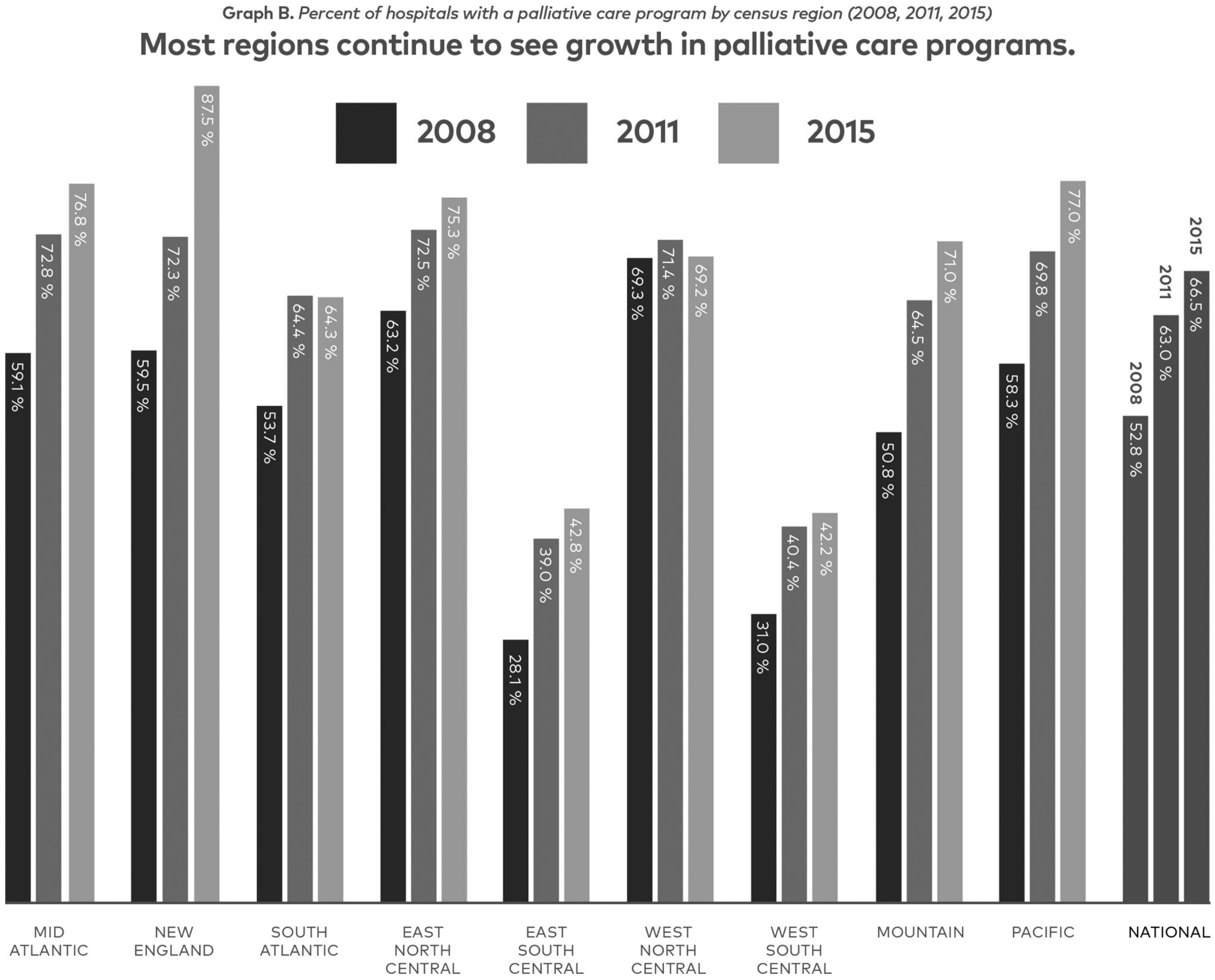


Figure 3.2 Percent of hospitals with a palliative care program by census region (2008, 2011, 2015).
Source: Center to Advance Palliative Care.

Economic Issues

Palliative care has been demonstrated to lower costs for both hospitals and payers by reducing hospital lengths of stay as well as pharmacy and procedural costs. Cost savings (cost avoidance) were demonstrated when matching patients who had palliative care team involvement were compared with those patients who did not.[56] Although it is not the goal of palliative care to reduce costs, cost analysis of palliative care programs has demonstrated this to be the case.[56,57] Reduction in costs by palliative care intervention may occur in multiple ways. Patients and their families are often stressed and burdened by a serious illness. Many times, they are not clear about what to expect and may be experiencing the fragmentation of multiple specialty providers giving seemingly conflicting messages. Compounding this is the erroneous societal expectation that medicine can fix nearly any health challenge. It is no wonder that patients and families sometimes have unreasonable expectations and are unable to discern the larger picture when functional status is declining and treatment options offer fewer benefits to quality or quantity of life.

In HBPC, clinicians may be able to provide the family with "the big picture" of the illness situation. As an "objective" assessor, the palliative care provider is particularly skilled at summarizing all relevant information and assisting the patient to match treatments with his or her own personal values and preferences. In so doing, patients and families are better able to apply their personal wishes and goals to the care that is being offered. They may elect to decline certain diagnostics or invasive treatments in favor of those that will provide comfort. Some may choose to not escalate care or perhaps to discontinue treatments that were previously initiated. In the setting of a prolonged critical care stay where treatments are no longer resulting in positive progress, a palliative care consult may result in de-escalation of disease-modifying care in favor of increasing "low-tech" comfort care. Such changes in treatment can result in reducing suffering of the patient and family and, at times, can also result in significant cost avoidance.[58,59] In the less costly hospital care that occurs in the critical care unit, the palliative care team can assist patients and families to select medical treatments and care that are consistent with their values and preferences.[58] When patients and families have a clear understanding of their prognosis and realistic information about proposed procedures or treatments, they may wish to decline further hospital care and return home. In some situations when symptom relief procedures or family respite is indicated, palliative care involvement can facilitate timely occurrence of the needed procedures so that time in the hospital is minimized. Not only does this potentially reduce costs, but quality of care is also enhanced.[58,59] In settings of seemingly futile care or conflict among healthcare providers, patients, and families or among healthcare providers, involvement of palliative care in conjunction with an ethics committee consultation may help achieve more rapid conflict resolution. Cost savings can be accomplished in indirect ways as well.[59] When the palliative care team is involved, they can spend the time at the bedside necessary to manage pain and other symptoms. This is invaluable to an already overburdened primary treating team, who may be working with other patients who also have intensive care needs. Thus, QOL and satisfaction for the patient and family as well as professional colleagues is enhanced. The palliative care team may also be invaluable in assisting with complex plans for discharge, coordinating care across settings, and enhancing communication between the treating team and the patient and his or her family.

Influencing Institutional, State, and National Policy

It is not enough to provide excellent, comprehensive care to just those patients who are referred for consultation. The truly effective HBPC program must seek out ways to influence care for all patients with life-limiting illness by developing an awareness and ability to influence healthcare policy within its institution and at a state or national level.[60] The influence should begin within the larger organization in two main ways: (1) by developing policies, procedures, and practices that will guide the care of all persons with life-limiting illness within the agency and any affiliates and (2) by integrating palliative care education and competency standards into basic orientation and continuing (preferably mandatory) staff education. Examples of the former include development of consultation triggers, policies for advance care planning, limitations of life-sustaining treatments, "comfort measures," withdrawal of mechanical ventilation, and standardized pain and symptom assessment and management. This type of influence will likely necessitate regular or ad hoc participation or leadership on institutional practice or ethics committees. Staff orientation has grown in sophistication, such that "simulated" patients and learning labs are becoming standard mechanisms for learning basic care skills. Practicing skills of communicating bad news, holding family meetings, and discussing advance care planning are some possible activities that lend themselves to such environments. Similarly, most organizations hold staff accountable for mandatory CPR certification. It would seem reasonable to require mandatory "do not resuscitate" classes in which staff learns effective care to provide when patients are near death but will not be resuscitated. Other educational endeavors include annual presentations at other departments or affiliated agencies' grand rounds on palliative care topics. Also, holding annual regional palliative care conferences for professionals or the public can bring attention to the program. Acting locally at the state level in legislative or health policy forums can make a big difference in care of patients.[61] Some states have palliative care or EOL task forces that make policy and legislative recommendations that will enhance the care of the seriously ill. For example, the Palliative Care and Hospice Education and Training Act (PCHETA; HR 1676/S 693) was introduced in March 2017 as bipartisan legislation intended to address the growing need for palliative care in the United States: PCHETA was drafted to strengthen training for palliative care team providers and improve palliative care teaching and research. Additionally, its intent is to generate national education programs to enlighten medical professionals, patients, and families about the benefits of palliative care and hospice. It also directs the National Institutes of Health (NIH) to use existing funds and authority to expand palliative care research and create academic and career incentive awards by providing grants or contracts to health professionals who agree to teach or practice in the palliative care field for at least 5 years (see https://www.congress.gov/bill/115th-congress/house-bill/1676). Collaborating with local organizations also lends power to individual efforts. For example, the NHPCO, the American Cancer Society, nursing and medical associations, and professional organizations at local, state, or national levels often have lobbyists and resources to assist with legislative efforts. Chapter 74 contains a broader discussion on the nursing role in policy development. However, it is important for HBPC program staff and leaders to keep these initiatives in mind as they develop within a healthcare setting.

Future Directions

Despite a strong foothold within mainstream medicine, there is always the continued need for growth, improvement, and education to sustain and expand palliative care. Collaborating to build systems of compassionate care needs to be balanced with moral ideals as well as institutional realities. This will eventually lead us to, as Senator Ted Kennedy said, "the humanization of our healthcare system." Therefore, it is vital that we strive to be agents of change in both our practice as well as on the state and national levels, to help carve the granite of health policy to assure it is meeting the needs of all patients. Our forward movement must include a dedication to assure integrated palliative care across healthcare settings with proper reimbursement.

External agencies must require mandatory adherence to standards, and those agencies that meet established standards should be properly reimbursed for their performance. Funding for palliative care research, adequate reimbursement, and support for faculty development must become national priorities. The growing consumer demand for patient- and family-centered care may be the "tipping point" that will make palliative care services an integral part of every organization that touches the lives of persons with life-limiting illness and their families. As awareness for palliative medicine interventions for the advanced illness patient evolves, it is our moral imperative that provides the clearest rationale: "Be kind whenever possible. It is always possible" (Dalai Lama). In every action taken, let us endeavor to always practice with kindness, and let kindness be the driving force for changing the face of healthcare delivery.

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CHAPTER 4

Principles of Patient and Family Assessment

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Key Points

- Comprehensive assessment of the patient and family is essential to planning and implementing palliative nursing care.
- Assessment involves input from the patient, family, and all members of the interdisciplinary team with information shared verbally as well as in the patient's health records.
- Ongoing, detailed, and comprehensive assessment is needed to identify the complex and changing needs and goals of patients facing chronic or life-threatening illness and those of their families.

Introduction

An effective assessment is crucial to establishing an appropriate nursing care plan for the patient and family. The palliative care nursing assessment may vary little from a standard nursing assessment.[1,2] To assess effectively, nurses working at the generalist level and at the advanced level of practice and other members of the interdisciplinary healthcare team must maximize their listening skills and minimize making quick judgments. Clinicians must actively explore both their initial hunches and alternative hypotheses to minimize premature closure.[3] Nurses use the therapeutic use of self to engage patients and families during the assessment, including the tools of active listening and the appropriate use of silence.

The goals of the palliative care plan that evolve from the initial and ongoing nursing assessments focus on maximizing quality of life (QOL). The quality-of-life framework by Ferrell et al.[4] is used to organize the assessment. The four quality-of-life domains in this framework are physical, psychological, social, and spiritual well-being. For this chapter, the psychological and social domains are combined into one: the psychosocial domain.

Because the needs of patients and families may change throughout the course of a chronic or life-threatening illness, these quality-of-life assessments are examined here at four critical stages along the illness trajectory: (1) at the time of diagnosis; (2) during treatment, that is, initial treatments and subsequent planned or unplanned treatments focusing on cure; (3) after treatment, that is, when the planned course of treatment is completed or when the patient's goals shift away from curing the illness; and (4) during active dying.

Effective palliative care assessments are predicated on nurses understanding their thoughts, values, emotions, convictions, and experience with respect to issues commonly arising in palliative nursing care. Nursing leaders agree that self-awareness and understanding one's perspectives are essential to providing quality nursing care.[5] Self-awareness has been demonstrated not only to improve quality of care, but also to decrease stress on the part of nurses' patients and patients' families.[6] Box 4.1 comprises some of the issues that palliative care nurses might explore about themselves to enable their effective assessments.

Chronic and Life-Threatening Illnesses

The experiences of seriously ill patients are dynamic in terms of the continuous or episodic declines they face throughout the illness trajectory. These experiences are associated with the trajectory that is characteristic for the illness. For example, persons living with dementia experience a slow, gradual decline, frequently at home or in a memory unit of a long-term care facility. Persons living with chronic obstructive pulmonary disease (COPD), on the other hand, experience a gradual decline punctuated by exacerbations requiring hospitalization and treatment, oscillating between a quasi–steady-state of relatively stable symptoms and acute episodes of severe symptomatology. Also, persons with a cancer diagnosis may experience a cure and then be cancer-free for the rest of their lives, or they may experience a recurrence of their disease. Every illness has its distinctive trajectory, but every person's journey along that trajectory is unique.

The focus of care for palliative care patients is a frequently shifting balance between cure and palliation. At diagnosis, the focus is likely to be more curative, focusing on minimizing the impact of the disease process on the person, whereas managing symptoms and optimizing QOL are secondary foci. But, over time, as the illness progresses and the patient declines, the focus shifts and becomes increasingly more palliative; that is, reduction of symptoms and maximizing QOL become the primary foci while attempts to impact on the disease process are purely for the sake of comfort. Examples of these kinds of illnesses today include AIDS; cardiovascular, respiratory, gastrointestinal, hepatic, and renal diseases; diabetes; neurological disorders such as multiple sclerosis, cerebral palsy, amyotrophic lateral sclerosis, Parkinson's disease, and dementia; chronic and severe mental illnesses, such as schizophrenia and bipolar disorders; multiple types of cancer; and sickle cell disease. For some of these illnesses, the focus of disease management may include attempting to extend life through research with the hope of finding a cure.

Box 4.1 Questions for Self-Awareness Prior to Palliative Nursing Assessments

What do I believe about . . .?

- QOL
- suffering
- patient autonomy
- pain, treating pain, tolerance, and dependence
- death and dying
- advance directives
- code status
- organ donation
- funerals, burial, and cremation
- cultures other than my own
- the use of:
  - CPR
  - life support, ventilators, and tracheostomies
  - medically administered nutrition at end of life and feeding tubes (NG, OG, PEG)
  - medically administered hydration at end of life
  - medications that could hasten death

Could I authentically discuss . . .?

- QOL
- suffering
- patient autonomy
- pain, treating pain, tolerance, and dependence
- death and dying
- advance directives
- code status
- organ donation
- funerals, burial, and cremation
- cultures other than my own
- the use of:
  - CPR
  - life support, ventilators, and tracheostomies
  - medically administered nutrition at end of life, and feeding tubes (NG, OG, PEG)
  - medically administered hydration at end of life
  - medications that could hasten death

Would I feel comfortable . . .?

- including my last name when introducing myself to patients and families
- asking family members to leave the room if necessary
- asking others in the room to let the patient answer my questions without their help
- asking questions that are controversial
- asking questions that are personal
- talking with families of dying or dead patients
- touching patients who are dying or dead

Noncancer illness accounted for more than two-thirds (72.3%) of the admissions to hospice in 2016 as reported by the National Hospice and Palliative Care Organization,[7] the distribution of which is listed in Table 4.1.

Persons diagnosed with a chronic or life-threatening illness may repeatedly alter their expectations about the future. Words describing the status of the disease during a cancer illness, for example, include "no evidence of disease," "remission," "partial remission," "stable disease," "recurrence," "relapse," and "metastasis." Noncancer illnesses such as heart failure (HF) and COPD are described by words such as "exacerbation" and "recovery." Mental illnesses are often episodic with episodes of "stability" punctuated with episodes of "decompensation" or "relapse." Patients and families report experiencing a "roller-coaster ride" in which the hopeful points in better health are often followed by crises with relapse or disease progression. Patients may be told, more than once, that they are likely to die within a short period of time only to recover and do well for a period. As a result, the finality of death may be more difficult when it does occur because, up to this point in the patient's trajectory, the disease has always responded to treatment.

Case Study: Hibaaq

Hibaaq is a 65-year-old married female patient of Somali descent. She was raised Muslim and considers herself adherent to her faith, and she has just been diagnosed with COPD/chronic bronchitis. Although she and her husband Liban had no history of smoking, they had been working in a chemical factory since their arrival in the United States more than 40 years ago. Liban is considering retirement soon. They live with their three children: 30-year-old son Rooble, 28-year-old daughter Sagal, and 20-year-old daughter Ubex.

Table 4.1 Major diagnoses for hospice admissions in 2016

Diagnosis	% of all hospice admissions
Cardiac and circulatory	18.7%
Dementia	18.0%
Respiratory	11.0%
Stroke	9.5%
Other	15.6%

Source: *NHPCO Facts and Figures: Hospice Care in America*. Alexandria, VA: National Hospice and Palliative Care Organization; 2018. https://www.nhpco.org/sites/default/files/public/Statistics_Research/2017_Facts_Figures.pdf.

Patient and Family Assessment

Introduction to Physical Assessment

Nurses understand that QOL is based in part on the severity and impact of physical symptoms. Physical assessment not only provides a baseline of symptoms at one point in time, but also monitors their changes, the emergence of new symptoms, the effectiveness of their treatments, and changes in how they impact on the patient's QOL. Physical assessment can uncover symptomatology in the psychosocial and spiritual domains as nurses use the *therapeutic use of self* when assessing and caring for patients and their families.

Physical assessment focuses primarily on organ systems and symptoms related to their functioning. Historical information can come from the electronic health record (EHR) to understand documented details from previous assessments done by others on the interdisciplinary care team, including diagnostic lab results and imaging. Subjective information is collected by talking to the patient and developing a picture of how they view their health and health status. Data are also triangulated with caregivers, frequently family and friends. During the interview, the nurse reviews each organ system with the patient to collect data on symptoms. The nurse develops objective information by doing a physical examination. Observing a patient's facial expressions, the nurse may notice nonverbal signs of pain. Auscultating heart sounds can shape an understanding of circulation changes and, thus, ischemic pain. The abdomen can deliver information about bloating and constipation through auscultation and palpation. Percussing the lungs can provide data about respiratory status and, thus, dyspnea.

Physical assessment also includes a determination of functional status. Various scales have been shown to be predictive of survival in specific classes of palliative patients based on an assessment of

Table 4.2 A framework for psychosocial assessment

Types of loss		
Physical loss	**Psychosocial loss**	**Spiritual loss**
Body function	Alterations	Hope for the future
Body parts	Autonomy	Illusion of control
Energy	Body image	Illusion of immortality
Mobility	Lifestyle	Illusion of predictability/certainty
Pain	Money	Time
Sexuality	Relationship changes	
	Role function	
	Sense of mastery	
	Sexuality	
	Time	
	Work changes	
Types of responses to loss		
Observing emotional responses	**Identifying coping styles**	
Acceptance	*Functional:*	
Anger	Normal grief work	
Anxiety	Problem-solving	
Bargaining	Humor	
Denial	Practicing spiritual rituals	
Depression	*Dysfunctional:*	
Sadness	Addictive behaviors	
Shock	Aggression	
Withdrawal	Fantasy	
	Guilt	
	Minimization	
	Psychosis	
Personal needs associated with loss		
Assessing the need for information	**Assessing the need for control**	
Wants to know details	Very high	
Wants the overall picture	High	
Wants minimal information	Moderate/average	
Wants no information, but wants the family to know	Low	
	Absent, wants others to decide	

Table 4.3 Differentiating normal grief from depression

Parameter	Depression	Normal grief
Anger	No expression of anger	Open expression of anger
Course	Frequently not self-limited	Self-limiting but recurrent with each additional loss
Crying	Crying absent or persists uncontrollably	Crying is evident and provides some relief
Dreams	No memory of dreaming	Dreams may be vivid
Emotions	Consistent dysphoria or anhedonia (absence of pleasure)	Emotional states variable
Energy	Extreme lethargy, weight loss	Lack of energy, slight weight loss
Intervention	Adaptation requires professional treatment	Adaptation does not require professional intervention
Losses	May not identify loss or may deny it	Identifies loss
Preoccupation	Self-preoccupied, rumination	Preoccupied with loss
Sleep	Insomnia or hypersomnia	Episodic difficulties sleeping
Social interaction	Socially unresponsive, isolated	Socially responsive to others

their functional status. For example, the Palliative Performance Scale (PPS) allows the nurse to assign a number on a 10-point scale (0–100% in increments of 10%) of functional status based on five observed parameters: ambulation, activity and evidence of disease, self-care, intake, and level of consciousness.[8]

Introduction to Psychosocial Assessment

Persons diagnosed with a chronic or life-threatening illness experience many losses. Responses to illness, however, vary tremendously among individual patients and family members. In addition, the same person may respond differently at various times during an illness. How a patient copes depends on the severity of the illness, the patient's history of coping with stressful life events, and available supports. Some individuals develop coping styles that are more helpful than others when facing a life-threatening illness.

Tables 4.2, 4.3, and 4.4 provide a framework for three key elements of psychosocial assessment: (1) conducting the psychosocial assessment, (2) distinguishing nonpathological grief from depression, and (3) doing a general mental status assessment. Throughout the illness trajectory, nurses use these tools to monitor patient response to illness and treatment.

Nurses assess two very important parameters to assist patients and families to cope in the most functional way possible. These parameters are (1) the need for information and (2) the need for control in making decisions. Observers of exceptional patients—persons who have thrived despite their prognosis—have noted that patients who are proactive and assertive information seekers often appear to experience better outcomes than patients who are passive in making decisions.[9] Indicators of a person's need for control may include:

- An expressed need for information.
- Comfort in asking questions.
- A willingness to assert their own needs and wishes relative to the plan of care.
- Initiative taken to research print and Internet resources on the illness and treatment.

Table 4.4 General mental health assessment

Appearance
Hygiene
Grooming, makeup
Manner of dress (appropriate, inappropriate)
Posture
Body language

Mood and affect (congruence)
Interview behavior
Specific feelings expressed
Facial expressions

Intellectual ability
Attention (distractibility)
Concentration
Concrete/abstract thinking
Comprehension
Insight into situation, illness
Judgment
Educational level

Sensorium/level of consciousness
Alert
Drowsy
Somnolent
Obtunded
Stuporous
Unresponsive

Psychomotor behavior
Gait
Observable symptoms (tics, tremors, perseveration, pilling)
Movement (akathisias, dyskinesias)
Coordination
Compulsions
Energy

Speech
Pressured, slow, rapid
Goal-oriented, rambling, incoherent, fragmented, coherent
Relevant, irrelevant
Poverty of speech
Presence of latencies (delayed ability to respond when conversing)

Thought patterns
Loose, perseverating
Logical, illogical, confused
Oriented, disoriented
Poorly organized, well organized
Tangential, circumstantial
Preoccupied, obsessed
Paranoid ideas of reference
Delusions
Hallucinations
Blocking, flight of ideas
Neologisms (made-up words)
Word salad (meaningless word order)
Presence of suicidal or homicidal ideation, plan, access to means

Table 4.2 provides details for doing a psychosocial assessment. More detailed information on the psychosocial aspects of cancer patients can be found in Holland's *Psycho-Oncology*.[10]

Some patients with advanced disease have been able to integrate their losses in a meaningful way, managing to reconcile and transcend them. An example of such a person is Randy Pausch, a late computer science professor at MIT who reported in his *Last Lecture*[11] on making meaning of living with a terminal diagnosis of cancer. And, of course, while all this is going on with the patient, family members are also going through a myriad of their own responses, which often are at different rates and intensities within the same family unit. Randy Pausch's wife Jai Pausch recounts her journey in *Dream New Dreams*.[12] (For more information, see Chapter 32 of this volume, "Supporting Families and Family Caregivers in Palliative Care.")

Grief is a normal reaction to loss, especially a major loss such as one's health. Nurses understand that although persons may be experiencing normal grief, ineffective adaptations or coping can indeed lead to depression.[13] Criteria for depression in the *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition (DSM-5)[14] include grieving the loss of a loved one, *but only if other criteria for depression are met*. In chronic illness, grief is also likely to be recurrent as losses accumulate and the patient and family reexperience these losses. This does not make it pathological, but it does form the basis of the roller-coaster phenomenon that many patients describe, one that can lead to a more pathological depression.[15,16] Table 4.3 compares normal grief with depression.

In some cases, patients may appear to be having difficulties in coping, but the nurse cannot easily identify the specific problem. The nurse may need to make a more thorough mental health screening assessment to determine the most appropriate referral.[17] Key elements in such an assessment are found in Table 4.4. In such instances, a referral to a behavioral health professional may also be warranted. Additional information and tools used to assess for emotional distress can be found in Chapter 52, "Palliative Care Nursing in the Outpatient Setting."

Introduction to Spiritual Assessment

Although Chapter 34, "Spiritual Screening, History, and Assessment," provides additional information on collecting information on the spiritual domain, the following discussion illustrates the importance of including the spiritual domain as a component of a comprehensive nursing assessment.

Attempts to define spirituality can often result in feelings of dismay and inadequacy. It is like trying to capture the wind or grasp water. Assessing and addressing the spiritual needs of patients, therefore, can be a formidable challenge. Spirituality may include one's religious identity, beliefs, and practices, but it involves much more. The person without an identified religious affiliation is no less spiritual. Indeed, the desire to speak one's truth, to explore the meaning of one's life and illness, and to maintain hope are all fundamental human quests that reflect the depth of the spirit. Various definitions of spirituality have appeared in the literature over the past years. But spirituality is defined by consensus in the palliative care community as "a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices."[18 (p. 646)]

The spiritual issues that arise at the time of diagnosis of a serious or life-threatening illness are abundant and varied. As a person progresses through the phases of an illness, he or she is confronted with mortality, limitations, and loss. This frequently leads to questions such as "What is my life's purpose?," "What does all this mean?," "What is the point of my suffering?," "Why me?," and "Is there life after death?" Indeed, Viktor Frankl, in his classic work *Man's Search for Meaning*,[19] affirmed that the quest to find meaning is one of the most characteristically human endeavors. To find meaning in suffering enhances the human spirit and fosters survival.

According to Abraham Maslow's theory,[20] human needs can be placed on a hierarchy that prioritizes them from the most basic physical and survival needs to the more transcendent needs. Thus, a patient's ability and willingness to engage in dialogue about issues of meaning, to discuss successes and regrets, and to express his or her core values may occur only after more fundamental needs are addressed. This reality in no way diminishes the spiritual compared with the physical; rather, it supports the need for a interdisciplinary approach that provides holistic care of the entire person. For example, if a nurse relieves a young woman's cancer pain and a social worker secures transportation for her to treatments, the patient and her family may be more able to address the vital concerns of her soul. Religious or spiritual advisor consultation may be indicated.

Responding to the spiritual needs of patients and families is not solely the domain of the chaplain, clergy, or other officially designated professionals. All members of the healthcare team share the responsibility of identifying and being sensitive to spiritual concerns. The sensitivity of the nurse to a patient's spiritual concerns improves the quality of palliative care throughout the illness trajectory. When members of the interdisciplinary healthcare team serve as companions to a patient and family during their journey with an illness, they offer vital and life-affirming care.

A patient must not be viewed in isolation, but rather in the context of those who are affected by the illness. The focus of spiritual assessment, therefore, includes not only the patient, but members of the patient's family—however the patient defines his or her family—including people not related to the patient by blood, marriage, or adoption, such as friends, neighbors, their faith community, and unmarried partners, and in traditional and nontraditional configurations. This perspective affirms the power of a systems view, the view that places the patient at the center of care while still being integral to the interdependent and connected family. Spiritual support to family members not only assists them directly but also may contribute to patient comfort secondarily: comfort may increase as the patient sees his or her loved ones being cared for as well.

The purpose of a spiritual assessment is to increase the healthcare team's knowledge of the patient's and family's sources of strength and areas of concern to prepare for planning quality care that maximizes patient and family QOL. The methods of assessment include direct questioning, acquiring inferred information, and observing. As with the physical and psychosocial domains, this is most effectively accomplished when a basis of trust has been established. The interdisciplinary team best serves patients' and families' needs when they determine whether the patient is experiencing spiritual distress and desires specialized spiritual care. Some patients are connected to a spiritual community and, when experiencing spiritual distress, look to their established community and leadership, such as a minister, priest, rabbi, imam, or other religious figure, for support. Patients without an established

Box 4.2 Spiritual Screening Questions

- Is religion or spirituality important to you?
- If so, does your religion or spirituality give you comfort?
- If not, has there ever been a time when spirituality or religion was important to you?
- Would you like me to contact anyone in your faith community?
- Would you like a visit from your faith community leader?
- Would you like a visit from a chaplain?

connection to a spiritual community tend to fall into one of three groups: (1) those who may be experiencing spiritual struggle but are unlikely to request spiritual support, (2) those who would like spiritual support but may or may not request it and would be dissatisfied if they did not receive it, and (3) those for whom religion and spirituality is not important and who would not want a visit from a chaplain or any spiritual support person.

The nurse's role historically includes being able to support the patient's spiritual life and concerns. A body of knowledge and cultural practices prescribe and confer the specific role—such as minister, priest, rabbi, imam, or other religious figure—with certain privileges to function as a companion to those patients who are addressing religious and spiritual concerns. Linking the patient with these professionals based on a sensitive screening of needs will enhance the patient's healing and integrative process. The Rush Protocol[21] is a tool to discern among these groups of patients and to respond more effectively to their needs and preferences. Box 4.2 is a summary of the kinds of questions useful for the nurse to ask as part of a spiritual screening.

One of the fundamental principles underlying spiritual assessment (and spiritual care) is the commitment to the value of telling one's story.[22] Alcoholics' Anonymous,[23] a very successful program with spiritual tenets, acknowledges the power of story. This might be paraphrased as follows: in the hearing is the learning, but in the telling is the healing. Park[24] presents the concept of a person's global meaning, their internal mechanism of making sense of the world.

Simple, open-ended questions such as "How is this illness affecting you?" and "How is the illness affecting the way you relate to the world?" provide the opportunity for validation of the patient's global meaning and placing her or his response to the illness within it.

Cultural Competence

The Joint Commission defines cultural competence as "the ability of health care providers and health care organizations to understand and respond effectively to the cultural and language needs brought by the patient to the health care encounter."[25 (p. 1)] Expecting that healthcare professionals will know all the customs, beliefs, and practices of patients from every culture is unrealistic, of course, and to do so promulgates the notion of stereotypes. All providers, however, should strive for some degree of cultural competence by being aware of differences and being open to asking appropriate questions to relate back to plans of care. Reference sources are useful to nurses and other members of the interdisciplinary team in gaining background information for cultural competence.[26] But the transformational nurse will ask the questions appropriate to building the nursing database.

Nurses and other members of the interdisciplinary healthcare team assess in culturally competent ways when they:

- Are aware of one's own ethnicity, biases, and ethnocentrism, the unconscious tendency to assume that one's own worldview is everyone's worldview or is somehow superior. This is especially important with differences viewed by some as moral choices, such as persons of different religious views, sexual orientation, or nonconforming gender.[27]
- Convey respect.
- Solicit the patient and family as teachers and guides regarding cultural practices.
- Ask about the patient's personal preferences, such as food, spiritual beliefs, family relationships, music, communication preferences, and interpersonal customs.
- Avoid expectations for any individual to represent his or her whole culture.
- Assess the patient's and family's beliefs about illness and treatments.
- Respect cultural differences regarding personal space and touch: "Whom do I ask for permission to examine you?" and "May I touch you here?"
- Determine needs and desires regarding health-related information: "When I have information to tell you, how much detail do you want to know and to whom do I give it?"
- Note and affirm the use of complementary and integrative healthcare practices: "Do you ever consult a healer or a person who provides medicines to persons in your community?"
- Are sensitive to the need for interpreter services[28] (Box 4.3) and engage professional interpreters who maintain compliance with the Health Insurance Portability and Accountability Act (HIPAA) for relaying information, instead of relying on family members to interpret.[29]

Box 4.3 Meeting the Need for Interpreter Services

Overview

- Medical interpretation can occur with an onsite face-to-face translator, a telephone-based interpreter, or a video-based interpreter over the Internet.
- Skills of a medical interpreter are not just the ability to interpret quickly and exactly between two languages, but also the ability to provide a cultural interpretation and context.
- A child or family member should not be used as an interpreter for major explanations or decision-making about healthcare. Even adult children may feel uncomfortable speaking with their parents or grandparents about intimate topics. Furthermore, many lay people do not know or understand medical terms in their own language. Informed consent requires that the patient receive accurate information that he or she can understand before making a healthcare decision.

(*continued*)

Box 4.3 Continued

- Use the services of a certified medical interpreter, if possible. See the websites for the International Medical Interpreters Association (http://www.imiaweb.org/) and the National Board of Certification for Medical Interpreters (http://www.certifiedmedicalinterpreters.org/) for more information.

When Working with an Interpreter in Healthcare

- Speak directly to the patient, not the interpreter. The interpreter should divert their eyes away from the patient and you as a nod to their role as a nonparticipant.
- Use simple language and ask open-ended questions. Be patient for the answers.
- Observe nonverbal communication and inquire of the patient what these might mean.
- Ask that any educational information be repeated back to you from the patient.

Services

- Several telephone-based interpretation services are available. AT&T and Language Line provides translation services by subscription or on a pay-as-you-go basis (http://www.languageline.com). The partnership is also making interpretation services more accessible via smartphones and has a video-based interpreting service for 35 languages, including American Sign Language (ASL).
- RTT Mobile and Sprint have partnered to provide a device initially for use by emergency responders and hospitals to communicate with persons with limited English proficiency. Called ELSA, the device immediately connects the service provider with an interpreter in the requested language over the Sprint network, enabling instant communication (http://www.rttmobile.com/interpreters). It is now used by healthcare providers and other industries around the world.
- Many online, video-based interpretation services are available. Cloudbreak provides a service called My Accessible Real-Time Trusted Interpreter (MARTI). It is HIPAA-compliant and available 24/7, 365 days a year by subscription (http://www.marti.us).

Review of the Electronic Health Record

Before meeting a patient or family member, the nurse prepares for the face-to-face encounter. This is done by reviewing the patient's EHR and developing an understanding of the nature of the patient's journey thus far: the initial nursing database. With the advent of the EHR and its emergence in hospitals, clinics, and primary care offices, access to up-to-the-minute patient data supports thorough preparation prior to making face-to-face contact with patients and their families. Also, palliative care patients are often very ill and do not have the energy or patience for, or interest in, answering myriad questions—especially if the questions do not relate to their immediate needs. The nurse conducts individualized assessments based on prioritized symptoms for each patient, therefore, based on the initial review of the EHR.

Beginning with the database prior to the initial face-to-face encounter will assist the nurse to focus assessments and increase the effectiveness of the time spent with patients and their families. Frequently, for patients in hospitals and other facilities, the nurse will print portions of the EHR, particularly the face sheet and the most recent history and physical examination, and write on them while building the nursing database from the EHR and during the face-to-face assessment interview. With increasing experience and expertise, the nurse will be able to streamline the amount of data needed to be written down, but all relevant data are always reviewed.

Although the three domains are discussed separately in this chapter, the nurse understands that holistic, interdisciplinary care of patients and their families often leads to interweaving of the domains during not only the review of the EHR but also face-to-face assessment encounters.

The nursing review of the EHR should reflect an understanding of the following:

- *Demographic information*: Note the patient's name and identification number, age, date of birth, gender, ethnicity, primary language, and occupation. The patient's address and phone number may become important for discharge planning and if advance directives (see later discussion) must be completed. Among the demographic information to collect are the names and contact information of any other service providers who have participated in the patient's journey, such as healthcare professionals, home health agencies, and clergy. If in an inpatient context, also note the room number and bed number of the patient.
- *Referral information*: Note whether the patient was referred for palliative services from another healthcare provider and, if so, the date of the referral and the reason given by the referrer for the consult. This is often most important for billing, but also in developing rapport with the patient and others on the interdisciplinary team.
- *Next of kin and contact information*: Note any familial relationships, such as spouse, partner, significant other, children (adults and minors), parents, and anyone else documented in the record. The nurse may want to document these relationships in a genogram (see Figure 4.1) to facilitate sharing of sometimes complex family structures. Some of this information may be documented in the EHR by other contributors of the interdisciplinary team, such as social work, case management, and pastoral care. Although HIPAA requires protection of personal health information, some patients' identities and whereabouts are subject to an extra level of security, such as prisoners, abused persons, and public figures. This is noted in the nurse's database. Finally, if two patients on the census have similar names, such as Lucy Walls and Lucia Wells, the nurse notes it.
- *Primary point of contact*: Identifying one point of contact for the patient and the associated phone number will facilitate communication between the palliative care team and the family. This person—frequently a spouse, parent, nearest living relative, or eldest child—will often be the designated person for making the healthcare decisions that they know the patient would have made for him- or herself. This surrogate decision-maker will often be documented in the EHR as the "Healthcare Power of Attorney," "HCPOA," or "POA" (or sometimes "DPOA" for durable power of attorney). Should a person become unable to speak for him- or

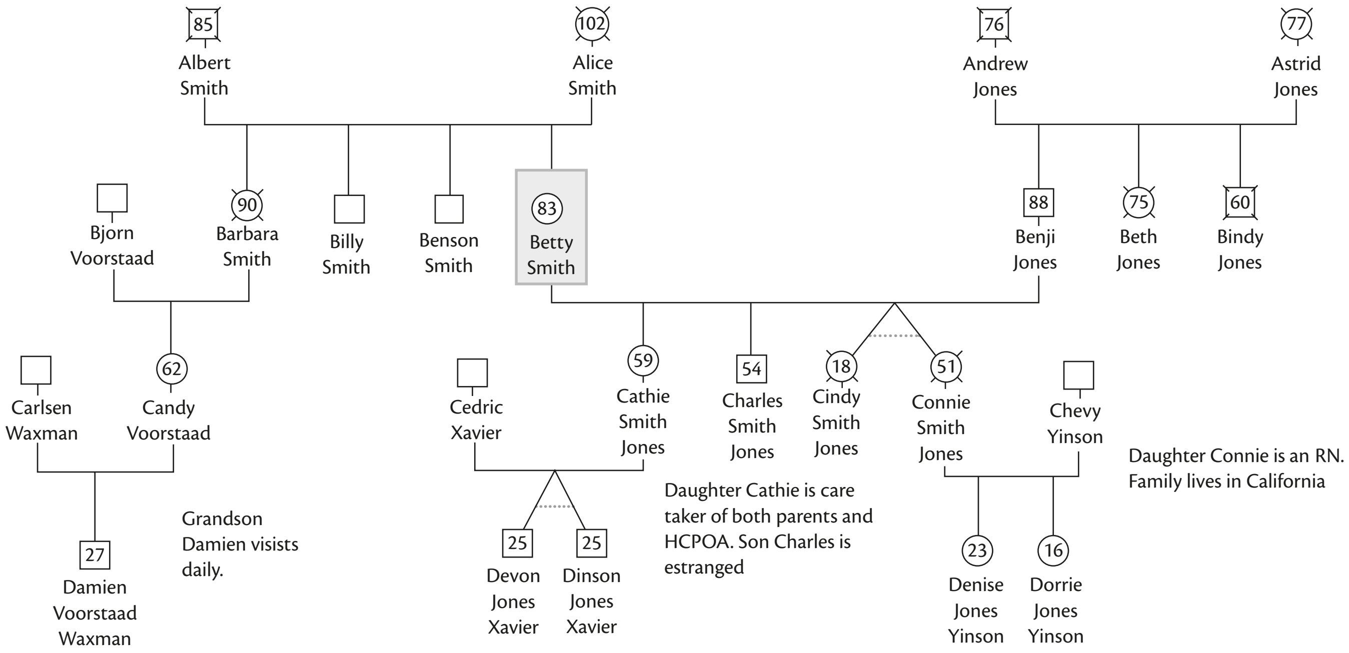
85
Albert Smith
102
Alice Smith
76
Andrew Jones
77
Astrid Jones
Bjorn Voorstaad
90
Barbara Smith
Billy Smith
Benson Smith
83
Betty Smith
88
Benji Jones
75
Beth Jones
60
Bindy Jones
Carlsen Waxman
62
Candy Voorstaad
Cedric Xavier
59
Cathie Smith Jones
54
Charles Smith Jones
18
Cindy Smith Jones
51
Connie Smith Jones
Chevy Yinson
Daughter Connie is an RN. Family lives in California
Grandson Damien visists daily.
27
Damien Voorstaad Waxman
25
Devon Jones Xavier
25
Dinson Jones Xavier
Daughter Cathie is care taker of both parents and HCPOA. Son Charles is estranged
23
Denise Jones Yinson
16
Dorrie Jones Yinson

Figure 4.1 An example genogram. Most assessment genograms will be sketched by hand.
Source: Illustration courtesy of John D. Chovan.

herself without having a designated surrogate to speak for him or her, most state laws designate a hierarchy of persons who are called on to speak for the patient, such as a court-appointed guardian, then a legal spouse, followed by adult children (sometimes as a group), siblings, other family members, and then other interested nonrelated parties. Distinguishing between the person who holds legal authority (power of attorney) for fiscal decision-making and the person who holds legal authority (power of attorney) for healthcare decision-making is important. If it is the same person or if the distinction is not obvious, the nurse clarifies this during the interview. Sometimes, engaging others on the team is needed to facilitate this clarification, such as chaplaincy or social work.

- *Religious affiliation*: Note the patient's stated religious affiliation and clergy, if indicated. Refer to the spiritual assessment information in this chapter for detailed information.
- *Advance directives and code status*: The Patient Self-Determination Act of 1990 requires all inpatient facilities to ask patients on admission if they have advance directives and, if so, to request a copy of them. Laws regarding advance directives and orders for code status are specific to each state, so the nurse must be familiar with the local laws for advance directives and orders for code status. A national movement to provide a way for the wishes of a patient to be explicitly stated in a single order from a healthcare provider, the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm,[30] is being implemented in various states and municipalities across the country. The presence or absence of advance directives and orders for life-sustaining treatment must be noted. The nurse reviews the documents and notes the patient's wishes as stated in them. If the documents are missing or incomplete, note that the missing data may be acquired during the assessment interview or referred to the resource persons (social worker or chaplain, for example) so designated at the nurse's institution. Also, note if the EHR indicates whether the patient is a registered organ donor.
- *Insurance coverage*: Patient care within the context of the US healthcare system is often delimited by the patient's resources. For example, Medicaid may have a restricted medication formulary. If the patient does not have adequate insurance coverage, consider a social work consult to help the patient access the necessary resources to obtain financial assistance.
- *Recent health trajectory*: Nurses may tap several sources of information in the EHR to develop an understanding of the patient's recent health trajectory and current health status. The most recent history and physical examination document (H&P) will describe the patient's diagnosis, history of the present illness, past medical and surgical history, and family and social history, all of which are pertinent to the provision of quality palliative care. It will also serve as a subjective and objective snapshot of the physiological state of the patient by organ system at the time the H&P was created as well as a summative impression of the health status of the patient at that time: the subjective review of systems, the functional assessment, and the objective physical examination. The functional assessment is particularly good at helping people not familiar with healthcare jargon to understand the changes in the patient across the illness trajectory and is typically reflected in the PPS score. The initial findings and plan of medical care are also included. The nurse continues to develop the picture of the patient's current state by reviewing the consultation notes by the other involved services and the recent progress notes, including other medical services and ancillary services, such as case management, dietary, respiratory therapy, physical and occupational therapy, and speech therapy. Note also the use and whereabouts of hearing aids, eyeglasses, and dentures, and the placement of ports, central lines, pacemakers, defibrillators, and implants.

- *Medications*: Review the patient's drug allergies and medications as listed in the EHR (home use and inpatient use), including over-the-counter and herbal preparations. Note if any newly ordered medications relate to the patient's comfort. Make note of medications that are or are not present for key symptoms including pain, dyspnea, anxiety, appetite, nausea, bowel function, and sleep, and for any symptoms mentioned in the H&P or indicated by the results of the diagnostic tests, such as lab results and reports from radiology and pathology. For example, patients with liver or kidney failure may have pruritus, and patients with a newly diagnosed chronic illness may have a depressed mood. Also note if any home medications can induce tolerance, such as some antidepressants and some pain medications. Stopping these medications abruptly could cause the patient to experience discontinuation or withdrawal symptoms. Persons who are stable on their home medications for hypertension, psychiatric issues, and other cardiac issues should not have their PO medications discontinued abruptly without additional input from care providers.
- *Diagnostic test results*: Objective information such as current vital signs and the results of diagnostic tests is important not only to understand the patient's current state but also to understand trends that inform the trajectory of the patient's illness and current symptoms. Trends in vital signs can indicate improving or declining status related to infections, oxygenation, and hemodynamic stability. Organ perfusion can be evaluated in part by indicators such as mental status changes, renal function tests, and liver function tests. In turn, functionality of these organs can affect the patient's plan of care. For example, the metabolites of morphine, a commonly used opioid analgesic, are excreted by the kidneys. When renal function is compromised (serum creatinine >2.0 mg/dL, or >1.5 mg/dL in older adults), the metabolites rapidly accumulate. Because they are neurotoxic, they can cause confusion. Drugs that are metabolized by the liver will lose their efficacy with compromised liver function, and the production of albumin—essential for functions such as drug transportation, wound healing, hemostasis, immune function, water and electrolyte balance, and muscle mass—and prealbumin (or transthyretin) can decline or cease. Levels of albumin (20-day half-life) are used to evaluate long-term nutritional status because they are thought to reflect the patient's nutritional status for the past few months. Prealbumin (2-day half-life) levels are thought to reflect nutritional status over the past few days, and, because absolute value of prealbumin may be influenced by other factors, trends in the prealbumin level are used to evaluate improvement during a clinical stay rather than specific values. Radiology and pathology reports may provide further information about symptoms and the severity and trajectory of the patient's illness, such as biopsy results, mass effects, and location of spinal compression fractures.
- *Complementary therapies*: Note the presence or absence of any complementary therapies the patient has used or those symptoms that may be amenable to available complementary therapies: creative/reactive modalities such as music therapy and art therapy; body energy work such as Reiki, Therapeutic Touch, and Healing Touch; introspective modalities such as guided imagery, meditation, and hypnotherapy; and interventional modalities such as massage therapy, aromatherapy, acupressure, and acupuncture.

At this point, the nurse will have a very good understanding of the data that are required to complete the assessment and the information that must be reconfirmed with the patient and family. The initial hypothesis of the holistic picture of the patient in all domains—physical, psychosocial, and spiritual—should begin to take shape.

Additional information is required to develop the most appropriate palliative plan of care for the patient and the family that can only be collected through a face-to-face interview.

The Initial Face-to-Face Encounter

The nurse is prepared to encounter the patient at any point in the trajectory of his or her illness because many people do not encounter palliative care services at diagnosis. Irrespective of when in the trajectory the nurse first meets the patient and family, the nurse establishes a relationship and begins to build trust with the patient and family—and other caregivers—as appropriate, at the first meeting and at every subsequent encounter.

Nurses and other members of the interdisciplinary healthcare team establish rapport and build trust when they:

- Find the nurse who is caring for the patient and ask about any issues the nurse might have become aware of during his or her care for the patient thus far. Note these issues in the database and add them to the list of items for further probing during the patient and family interview.
- Use hand sanitizer or wash their hands within view of the patient and family to demonstrate professionalism and concern for safety.
- Verify that this is the correct patient: check the armband, if applicable. If the patient is alert, begin the interview, "Good morning. What is your name?" If the patient is not alert, attempt to arouse the patient if possible. If the patient is not responsive, the EHR and/or the family may be the best source of information.
- Introduce themselves to the patient and others in the room with first and last name, role, and how the patient may address her or him: "My name is Jane Doe. I am a nurse practitioner on the palliative care team. Your attending physician Dr. Jones asked our service to see you, and I talked with your RN Josh this morning. You may call me Jane."
- Determine how the patient would like to be addressed: first name, last name, title, and/or nickname: "What may I call you?" Do not be surprised if a patient asks to be called something more formal than expected, such as "You may call me Mrs. Jackson," or by an unfamiliar name. Do not hesitate to ask how a name is spelled if in doubt.
- Identify the other persons in the room and their relationship with the patient: "Whom do we have in the room with us, Mrs. Jackson?" Sometimes the patient will introduce the individuals if he or she can, or the individuals in the room will introduce themselves. The nurse requests elaboration of the relationship between the patient and others in the room as appropriate. Modify the genogram as appropriate.
- Explain the purpose of the interaction and the approximate length of time expected that the nurse will spend with the patient: "Our team does several things including pain and symptom management, helping you to determine your goals, and keeping

you comfortable in the hospital. We will be spending about 20 minutes talking with you and examining you."

- Obtain the patient's permission to proceed with the assessment: "May I continue?," giving the patient an opportunity to get comfortable: "Do you need to use the restroom before we start?," and excusing others whom the patient does not wish to be present during the interview and examination: "Mrs. Jackson, do you want your visitors to stay here during our conversation or would you rather they step out of the room?" Some patients may want others to be present during the interview, to assist with recall—particularly patients with compromised memory—but not during the examination. The nurse modifies the assessment routine to accommodate the focused goals of the assessment and patient preferences.
- Take a seat near the patient, being respectful of the patient's cultural norms for physical closeness and eye contact, "Do you mind if I sit down next to you? So we can talk more comfortably?" Some patient rooms are very small, so the nurse is cognizant of his or her presence in the room and the most appropriate place to be seated to interact with the patient and family.

Completing the Nursing Database

Now that the nurse has begun to establish rapport and trust with the patient and the patient's family in the room, the nurse completes the nursing database using interview, observation, and assessment techniques drawn from all three domains. Nurses complete the nursing database when they:

- Invite the patient to describe how he or she learned of the illness: "So tell me, Mrs. Jackson, how you learned about your illness."
- Take care not to interrupt the patient too often; use communication techniques such as probing, reflecting, clarifying, responding empathetically, and asking open-ended questions to encourage greater detail if the patient's account is brief or sketchy.
- Proceed through the physical assessment, the psychosocial assessment, and the spiritual assessment (see later sections).
- Prepare to end the interview when appropriate, thus supporting patient-centered care: ask the patient and the family if they have any unanswered questions for which the nurse might assist with finding the answers and give them the opportunity to ask about something that is unclear or that they had not had the chance to ask earlier.
- Ask the patient and family if they can think of anything else that the nurse might do for them that would contribute to their comfort and close the initial interview by summarizing any action items.
- Bid everyone a professional goodbye as appropriate.

A growing issue that relates to family members' health is genetic testing for familial diseases. The nurse asks patients with diseases that could have a genetic origin whether they would be interested in receiving more information. Patients or family members who desire more facts will benefit from written materials and referral to an experienced genetic counselor. For a tool to support this assessment, refer to the American College of Preventive Medicine's Genetic Testing Time Tool.[31] The National Society of Genetic Counselors (http://www.nsgc.org) has an extensive listing of genetic counselors in the United States and around the world through the Find a Genetic Counselor tool (https://www.nsgc.org/p/cm/ld/fid=545).

Assessment at Diagnosis

The palliative care nursing assessment goals at the time of diagnosis are to:

- Determine the baseline health of the patient and family.
- Identify problems for which interventions can be planned with the patient and family that maximize their QOL.
- Uncover learning needs to guide teaching that promotes optimal self-care.
- Ascertain patient and family strengths to reinforce healthy habits and behaviors for maximizing well-being.
- Discern when the expertise of other healthcare professionals is needed, such as a social worker, registered dietitian, chaplain, or therapist.

Physical Assessment at Diagnosis

Nurses complete the physical assessment at diagnosis when they:

- Move through the review of systems to verify and update information in the nursing database.
- Avoid nursing jargon—terminology unfamiliar to the average person—such as the use of abbreviations, acronyms, and shortcut phrases (e.g., Q 4 HRS, PO, HS; UTI, CHF, and PEG; and tele, tachy, brady down, and Q-sign).
- Request permission to touch the patient: "Mrs. Jackson, now I would like to examine you. Is that OK?"
- Obtain data by inspection, auscultation, palpation, and percussion; observe and interview the patient as necessary during the examination; and explain each action in advance: "I'm going to listen to your lungs and heart, then your belly." The format, policies, procedures, and expectations of the healthcare agency in which the assessment occurs guide the specific details that are collected and documented. Box 4.4 shows cues to guide the review of systems, Box 4.5 shows cues to guide the functional assessment, and Box 4.6 shows cues to guide the head-to-toe physical assessment and PPS score.
- Assist with the discussion and decision-making about code status using language that does not confuse the patient and family. Such a discussion must be undertaken based on the goals established by the patient in conversation with the members of the healthcare team. The discussion should be in the context of the person's health status and an understanding of likely outcomes of an attempt to resuscitate. Possible negative outcomes of an attempt to resuscitate include pain and injuries, such as rib fractures, clavicular fractures, and tracheal bleeding from the trauma of chest compressions. If a patient's health is particularly compromised, include in the discussion the low likelihood that the patient would return to her or his current level of functioning should the resuscitation efforts be successful. If consistent with the patient's goals of care, one way to introduce the topic to the patient and/or family is, "We hope for the best, but try to prepare for the worst. I would like to ask you a few questions about your thoughts about care at the end of life. Have you thought about this? What would be important for you at the end of your

Box 4.4 Review of Systems

General

"In general, how have you been feeling?"

Weight changes

Changes in energy level

Changes in sleeping pattern

Fevers, chills, sweats

Pain: acute, chronic

P—Precipitates/Palliates: What happened when first noticed? What brings it on? What makes it better?

Q—Quality: Aching, burning, cramping, deep, stabbing, throbbing

R—Region/Radiation: Where is the locus of the pain? To where does the pain radiate?

S—Severity: Pain scale, 0 = no pain, 10 = worst ever

Acceptable level

Getting better, worse, or staying the same

T—Timing: Onset, constant or episodic, frequency, duration

U—Understanding: What do you think it means?

Head, eyes, ears, nose, throat (HEENT)

Head, neck

Head or neck pain—PQRSTU

Headache—PQRSTU

Eyes

How is your vision?

Changes, pain, discharge

Blurriness

Double vision

Photophobia

Redness

Excessive tearing

Tiredness

Ears

How is your hearing?

Changes, pain, discharge

Tinnitus

Vertigo

Nose, sinuses

How's your sense of smell?

Changes, pain, discharge

Postnasal drip

Congestion

Obstruction

Throat, mouth

Pain: Mouth, tongue, teeth, throat, swallowing—PQRSTU

Changes: Voice, swallowing, gums

Sores

Bleeding

Respiratory

How is your breathing?

Changes

Pain when breathing—PQRSTU

Dyspnea: At rest, on exertion, how far can you walk; tripoding

Cough: Productive, quantity, color

Wheezing: On inspiration, on expiration

Cyanosis: Lips, fingernails, toenails

Orthopnea: Sleep with pillows, how many

Sleep apnea, snoring

Paroxysmal nocturnal dyspnea

Cardiovascular

Chest pain (CP)—PQRSTU or pressure

Syncope: How often, for how long

Palpitations: Sense of rapid or irregular heartbeat, how often, for how long

Lower extremity edema

Leg pain with or without ambulation—PQRSTU

Wounds or ulcers in feet, slow healing

Gastrointestinal

Appetite

Difficulty swallowing

Heartburn—PQRSTU

Food intolerances

Nausea: How often, for how long, precipitates, palliates

Vomiting: Amount, color, how often, for how long, precipitates, palliates

Pain: Abdominal—PQRSTU

Abdominal swelling or distention

Flatulence

Bowel movements: Last BM, normal frequency (daily, Q2D, Q3D); incontinence

Stool changes: Form, frank blood, black and tarry

Constipation: How often, for how long, precipitates, palliates

Diarrhea: How often, for how long, precipitates, palliates

Hemorrhoids

Genitourinary

Pain—PQRSTU: Flank, suprapubic, dysuria

Frequency

Box 4.4 Continued

Urgency

Hesitancy

Strength of stream

Nocturia

Hematuria

Urinary incontinence

Incomplete emptying, still need to urinate when done

Hair changes: Pubic, axillary, other

Libido: Decrease, increase

Orgasm: Changes, anorgasmia

Fertility problems

Date of last breast self-exam

Breast, changes, pain—PQRSTU, discharge

For men:

Date of last genital self-exam

Penis: Changes, pain—PQRSTU, discharge

Scrotum: Changes, pain—PQRSTU

Arousal: Changes, ED, priapism, pain—PQRSTU

Intercourse: Changes, pain—PQRSTU, inability to complete to satisfaction

Ejaculation: Changes, delay, premature, pain—PQRSTU

Semen: Changes, amount, color, consistency

For women:

External: Changes, pain—PQRSTU, discharge

Menses: Changes, pain—PQRSTU

Intercourse: Changes, pain—PQRSTU, dryness, inability to complete to satisfaction

Musculoskeletal

Muscle ache—PQRSTU

Low back pain—PQRSTU

Pain, swelling, cracking, popping of joints

- Upper extremities: Shoulders, elbow, wrists, fingers
- Lower extremities: Hips, knees, ankles, toes

Bone pain—PQRSTU

Endocrine

Heat or cold intolerance

Polyuria, polydipsia, polyphagia

Changes in distribution of facial hair, body hair

Immune

Allergies: Respiratory, topical, food

Any unexplained inflammation

- Rubor—erythema
- Tumor—swelling
- Calor—warmth
- Dolor—pain—PQRSTU
- Functio laesa—loss of normal function

Hematology/oncology

Abnormal bleeding or bruising

New or growing lumps or bumps

Hypercoagulability

Skin and hair

Hair: Changes (color, texture), loss

Skin

Lesions: Changed size, shape, color

Eruptions, growths

Itching, pain—PQRSTU

Neurological

Tremors

Numbness

Weakness

Dizziness

Balance or coordination problems

Sudden loss of neurological function

Abrupt loss or change in level of consciousness

Witnessed seizure activity

Psychiatric

Mental status changes

Mood changes

New worry or anxiety

Changes in thought patterns

Memory changes

Box 4.5 Functional Assessment

Compare to before the illness, last month, 6 months ago, 1 year ago.

Activities of daily living

Bathing

Dressing

Personal grooming

Eating

Transfers

Toileting

Continence

Ambulation

Instrumental activities of daily living

Shopping

Meal preparation

(*continued*)

Box 4.5 Continued

Taking medications
Housekeeping
Laundry
Transportation
Telephone use/communication
Managing personal finances

Environment

Do you live alone?
Do you feel safe in your neighborhood?
Can you pay your bills for heat, water, and electric?
Do you drive or take the bus? Or something else?
Are you involved in any community activities?

Nutrition, diet

Appetite
Foods: Favorites, dislikes
24-hour food diary recall
Who buys and prepares your meals?
Can you afford to purchase food?
Nutritional balance

Coping

What kinds of stressors do you face every day?
Any significant stressors in the past year?
How do you try to relieve stress?
Is that helpful?

Exercise

Type
Amount
Warm-up
Monitoring response to exercise
What job do you do now? Or did you do before you retired?
Are any of your health problems related to exposure to something at work?

Abuse—How are things at home?

Domestic violence
Child abuse
Elderly abuse

Perception of health

How do you define health?
How do you view your situation now?
What are your concerns?

life?" Depending on the patient's or family member's responses, further conversation may be required regarding details such as the desire for resuscitative efforts (including chest compressions, defibrillation, and intubation) and for artificial life support (including mechanical ventilation, and medically administered nutrition and hydration).

Psychosocial Assessment at Diagnosis

The primary psychosocial feature of a new diagnosis is anticipatory grief. Patient responses and those of their family members to receiving bad news range from shock, disbelief, and denial to anger and fatalism. Statements such as, "I can't believe this is happening to me" or "Why is this happening to us?" are signals to the nurse that the patient and family are grappling heavily with this threat to life as they know it to be. There is already a sense that life will be forever changed. A longing emerges to return to the way things were.

In response to these emotional states, nurses and other members of the interdisciplinary team are most helpful when they:

- Normalize the patient's and family's experiences: "Many people share similar reactions to this kind of news."
- Use active listening skills to facilitate grief work: "Of all that is happening to you right now, what is the hardest part to deal with?"
- Create a safe space for self-disclosure and build a trust relationship: "No matter what lies ahead, you will not face it alone."
- Develop a collaborative partnership to establish a mutual plan of care: "What would help you the most right now?"
- Respect the patient's or family's use of denial in the service of coping with harsh realities: "It must be hard to believe this is happening."
- Assess the patient's and family's coping styles: "When you have experienced difficult times in the past, how did you get through them?"
- Reinforce strengths. "It sounds like this has helped you before."
- Maximize a sense of control, autonomy, and choice. "It seems you really have a handle on this."
- Assess the patient's need for information: "What do you know about your illness?," "Are you the kind of person who likes to know as much as possible, or do you function on a need-to-know basis only?," "What would you like to know about your illness now?"
- Check the need for clarification: "What did you hear?" or "Summarize in your own words how you understand your situation now."
- Mentor patients and families who have had little experience with the healthcare system, and coach them on having effective conversations with other members of the healthcare team. Suggest that they write down questions and the answers they receive, and teach them ways to navigate the complexities of the healthcare system.

Nurses must always remember that although the patient is feeling strong emotions when he or she first learns of the diagnosis, the family is also experiencing intense feelings. Similar assessments of family members will help to mobilize resources at critical times. Family members experience their grief reactions at their individual rates throughout the course of the patient's illness. Each family member has his or her own coping style and need for information.

Box 4.6 Physical Examination and PPS Score

General: Observe for patient disposition, acute distress, arousability; manner of dress, posture, body language, diaphoresis.

Vital Signs: Temperature, heart rate, respiratory rate, SpO_2, O_2 rate, O_2 delivery device, vent parameters, SBP/DBP.

HEENT:

- Head: Observe for shape and evidence of trauma.
- Eyes: Observe pupils bilat for shape and reaction to light and accommodation, retinal fundi, sclera, icterus, discharge, tearing, glasses, contacts, reading glasses.
- Ears: Observe external ear, ear canal, tympanic membranes bilat, cerumen, discharge, hearing aids.
- Nose: Observe for inflammation, obstruction, discharge.
- Neck: Palpate cervical lymph nodes for stiffness.
- Throat: Observe for jugular vein distention (JVD), thyroid location; palpate sublingual lymph nodes, thyroid; observe oropharynx, dentition, dental hygiene, dry or cracked lips. Auscultate carotid pulses bilat.

Respiratory: Observe chest excursion, use of accessory muscles, effort; palpate for tenderness; auscultate breath sounds all lobes anterior/posterior, appreciate adventitious sounds, rales, rhonchi, wheezing; palpate fremitus, crepitus; percuss for dullness.

Cardiovascular: Observe posture, edema, cyanosis, cardiac assist devices; auscultate heart sounds; palpate peripheral pulses (radial, pedal) bilat.

Gastrointestinal: Observe for distention, abdominal ascites, ostomy, rectal tube, stool; auscultate bowel sounds in all four quadrants; palpate superficially and deep; observe for rebound tenderness; percuss for margins of abdominal organs.

Genitourinary: Observe for presence of urine, volume, color.

Musculoskeletal: Observe for spontaneous movements of extremities, muscle strength, spinal flexibility, temperature, deformities; L/R comparisons.

Neurological: Observe for level of consciousness, orientation, grossly intact cranial nerves II-XII, sensation in all extremities, full range of motion (ROM) in extremities, cerebellar reflexes, tremors, Romberg, gait.

Psychiatric: Observe for mood, affect, anxiety, disordered speech, language, delirium, hallucinations, capacity for decision-making, memory, attention span. An example tool for screening of cognition is the Saint Louis University Mental Status (SLUMS) Examination.[32]

Integumentary: Observe for rashes, bruising, wounds, discoloration, mottling, lesions, nevi (ABCD), venous access ports, complexion, makeup.

PPS: Determine the patient's current PPS score based on observations and collected data about the patient's ambulation, activity and evidence of disease, self-care, intake, and level of consciousness.

Family: Assess and document the overall health of family members. Identification of the major health problems, physical limitations, and physical strengths of family members serves as a basis for care planning. The physical capabilities and constraints of the caregivers available to assist and support the patient may affect the plan of care, especially in relation to the most appropriate setting for care. This information also provides direction for the types of referrals that may be needed to provide care.

See Chapter 32, "Supporting Families and Family Caregivers in Palliative Care," and Chapter 65, "Supporting Adolescents with a Parent in Hospice," for additional information.

Nurses and other members of the interdisciplinary healthcare team assess the psychosocial domain at diagnosis when they:

- Assist in the process of making initial treatment decisions, which can be an opportunity to begin a relationship that will continue to grow. Members of the healthcare team may ask questions such as, "What is most important to you in life?" and "Is QOL or quantity of life most meaningful?" Assisting the patient and family in identifying and expressing their values will guide them in subsequent decision-making.
- Observe changes in family members' roles and responsibilities. For example, one member of the household may decide to stay at home to care for the loved one and no longer work outside the home, thus eliminating one source of family income, or the adult child may become the caregiver when the parent can no longer take care of her- or himself.
- Identify external community support systems such as a faith community, volunteer organizations, and transportation services.
- Assist the patient and family to identify coping strategies to use while awaiting answers from results of diagnostic tests and procedures. Waiting for results is not only one of the most stressful times but also a stressful time that recurs throughout the illness.

Spiritual Assessment at Diagnosis

The diagnosis of a serious illness generally brings with it a sense of shock to the patient and family. It may threaten many of their assumptions about life, disrupt their sense of control, and cause them to ask "Why?" At diagnosis, an important nursing assessment is to learn any spiritual practices that might have an impact on the patient's and family's healthcare decisions, such as avoiding various foods, not receiving blood products, and not being touched by a person of the opposite gender. Spiritual goals at this phase are to normalize initial concerns, provide information that fosters positive coping, inform the healthcare team of any special spiritual needs, and encourage the patient and family to seek supportive spiritual resources.

Nurses and the other members of the interdisciplinary healthcare team assess the spiritual domain at diagnosis when they:

- Determine the patient's and family's level of hopefulness or optimism about the future: "What are you hoping for?" or "How do you see the future?"
- Inquire about how the patient and family have dealt with past crises of faith, meaning, or loss: "What helped you get through that?"
- Determine the patient's and family's comfort level in talking about the spiritual life: "Some people need or want to talk about these things; others don't. How is it for you?"
- Inquire about spiritual support persons available to the patient and family, such as a priest, pastor, rabbi, imam, counselor, or spiritual advisor: "Is there a spiritual support person available to you? Does he or she know you are here?"
- Determine the patient's or family's need or desire to speak with a spiritual support person: "Would you like me to contact that spiritual support person for you?"
- Ask about spiritual practices that inform the healthcare team about caring for the patient and family: "Are there any spiritual practices that we should be aware of to help us take better care of you?"
- Ask about spiritual self-care practices to promote healthy coping: "How are you taking care of yourself at this time?"
- Listen for comments from the patient and family regarding the importance of their religious traditions and practices: "Well, she reads the Bible every day, but don't ask her about the last time she went to church."

Case Study: Hibaaq at Diagnosis: COPD

Over the course of the past years, Hibaaq had frequent productive coughs and colds, which she attributed to the fumes at work. She was reluctant to be seen by a provider because she was raised to believe that going to a healthcare provider would make her sick. One winter, she was having increased trouble breathing and reluctantly agreed with her younger daughter to see her primary care provider, who referred her to a pulmonologist. After collecting a history of her symptoms, doing a physical examination, collecting data on various COPD tools,[33] completing spirometry testing, and reviewing her blood tests, the pulmonologist determined that Hibaaq had COPD. Recommended treatment at this point was a long-acting beta-adrenergic agonist, and she was referred to a community palliative care program.

The palliative care assessment goals for Hibaaq and her family at the time of diagnosis are to:

- Assess Hibaaq for knowledge about her plan of care and readiness to adhere to the medical plan of care, as well as any roadblocks to doing so.
- Assess Hibaaq and her family for their need for resources so they can learn about how to live and cope effectively with this lifelong, incurable illness.
- Determine Hibaaq's and her family's need for supportive encouragement and to screen for depression and challenging behaviors, as well as the need for therapy and antidepressants.
- Assess for available spiritual supports and the need for a chaplaincy referral.
- Assess for readiness to discuss advance directives and the need for appropriate forms.

Assessment during Treatment

Reassessments during treatment determine the changes that have occurred since the initial assessment. They occur regularly during scheduled interactions with patients and families, as well as during any emergent crisis.

The palliative care nursing assessment goals during treatment are to:

- Assess the patient's systems in all domains that have a history of, or are at risk for problems, considering both changes from the patient's baseline problems and any side effects of the treatments.
- Identify the current and potential problems to plan early interventions with the patient and family, particularly as they approach decision points regarding treatment.
- Ascertain the need for teaching to prevent, minimize, and manage problems with the goal of maximizing QOL.
- Identify patient and family strengths, healthy habits, and behaviors to reinforce for maximizing well-being.
- Determine the need for other healthcare professionals' expertise to make appropriate referrals; for example, a referral to a physical therapist or a pharmacist.

Physical Assessment during Treatment

Knowledge of the usual disease process and of the side effects of treatment assists the nurse in focusing reassessments on those body systems most likely to be affected. The nurse begins to build a strategy during the assessment of possible nursing interventions and therapies that might be used to address disease progression and symptoms before they occur or worsen.

In addition to the patient's physical assessment, the nurse makes periodic observations and inquiries about the health of other family members. Documenting any changes in their health problems or physical limitations and physical strengths that might have an impact on the patient's care and the family's overall QOL is important. The nurse determines the PPS score and also documents changes in PPS score from the last documented assessment. Changes in PPS score have been shown to be better predictors of mortality than simply PPS alone.[34]

Psychosocial Assessment during Treatment

Once a treatment plan has been initiated, patients often express relief that "something is finally being done." Acting frequently reduces anxiety. The most important psychosocial intervention at this stage is the amelioration of as many treatment side effects as possible. After basic needs for physical well-being are assessed and symptoms are controlled, the patient can explore and meet higher needs, including the needs for belonging, self-esteem, and self-actualization.[20] Patients who are preoccupied with pain and nausea or vomiting have no energy or ability to explore the significance of their illness or their feelings about it. Effective management of physical symptoms is mandatory before the patient can begin to work on integrating the illness experience into the tapestry of his or her life.

After several months or years of treatment, the effects of having a chronic illness may exhaust even the hardiest person. Patients may begin to weigh the benefits versus the burdens of continuing aggressive therapies. Initially, patients will endure almost anything if they believe a cure is possible. As time unfolds, their attitudes may change as they watch their QOL erode with little prospect of a more curative outcome. Patients may also reprioritize what is most important to them. For example, the Type A personality may find less satisfaction at the office, or the stay-at-home parent may experience a lower level of fulfillment from daily routines around the house. Change, transition, and existential questioning characterize this phase, particularly while preparing to transition to the next phase.

Nurses and other members of the interdisciplinary healthcare team assess the psychosocial domain during treatment when they:

- Inquire about the patient's newly emerging identity as a result of the illness: "What activities and which relationships bring you the most joy and meaning?" or "Have you been able to define a new purpose for yourself?"
- Assess for signs of anxiety and depression, which remain the two most common psychosocial problems associated with severe illness (Table 4.5); for more information contrasting anxiety and depression, consult Holland's *Psycho–Oncology*.[35-37]
- Screen for suicidal ideation in cases of depression: "Have you been feeling so bad that you've been thinking of a way to hurt yourself?," "Do you have a plan for how to do it?," and "Do you have access to what you would use to carry out your plan?"
- Determine the need for counseling and possible psychotropic medication to enhance positive coping and comfort.

Spiritual Assessment during Treatment

With the treatment of a serious illness comes the introduction of an additional stressor to the patient and family. It is important to assess how they incorporate the demands of treatment into their daily routine and how these changes have affected the meaning of their lives. The spiritual goals during treatment are to reinforce positive coping, mobilize existing spiritual resources, invite the patient and family to develop new skills for self-care, update documentation of patient wishes as they evolve, and continue disclosures in an atmosphere of trust.

Nurses and other members of the interdisciplinary healthcare team assess the spiritual domain during treatment when they:

- Assess how hope is shifting: "What are your hopes for the future?"
- Assess the level and quality of support they are receiving, for instance, from other family members, faith community, and neighbors: "What kinds of support do you need?" and "Who is helping you out?"
- Explore expressions of anxiety and fear: "What is concerning you the most at this time?"
- Assess how the patient and family are coping with the rigors of treatment: "What is the most challenging part of this for you?" and "What is helping you day by day?"
- Determine the need for referrals to a chaplain or faith community as needed.
- Inquire about the patient's and family's definitions of QOL and the impact of treatment on these aspects of their lives: "What is most important to you in life now?"
- Determine their use of spiritual practices such as meditation, relaxation, prayer, or burning incense, for example, and offer assistance in developing them: "What are you doing to take care of your spirit?"
- Ask how the patient or family members feel about their current practices: "Are these helpful or not?"
- Assess the need for changes in the patient's advance directives and in code status: "Have you thought any more about who you would want to make your healthcare decisions for you if you were not able to make them yourself?," "Have you talked with your family about whether or not you want to be put on a breathing machine if you cannot breathe on your own?," "Do you still want a feeding tube if you need one?," "If you require dialysis to stay alive, do you want it?"

Case Study: Hibaaq during Treatment

Hibaaq often felt dyspneic, and although her husband insisted that she wear an oxygen mask as therapy, she did not find it to be very helpful. At times, she felt on the verge of panic when she was short of

Table 4.5 Assessing for anxiety and depression

Depression	Anxiety
Anhedonia (absence of pleasure)	Anorexia or overeating
Diminished ability to concentrate, make decisions, or remember	Compulsions (repetitive ritualistic acts)
Fatigue, decreased energy	Excessive worry
Feelings of worthlessness or inappropriate guilt	Frequent crying spells, headaches, gastrointestinal upsets, palpitations, shortness of breath
Insomnia and hypersomnia	Irritability, muscle tension
Marked weight loss or weight gain	Obsessions (persistent painful ideas)
Psychomotor retardation	Restlessness, agitation
Recurrent thoughts of death, suicidal ideation (lethality assessed by expressed intent, presence of a plan and the means to carry it out, previous attempts, and provision for rescue)	Self-medication
Sad mood (refer as needed)	Thoughts interfere with normal activities of daily living
	Trouble falling or staying asleep
	Unrealistic fears (phobias)

breath, and it could get so bad that she had someone take her to the hospital. Hibaaq had difficulty understanding why her illness was not improving. Her pulmonologist added an inhaled corticosteroid to her therapeutic regimen. As the years progressed, her functional status continued to decline, and her exacerbations became more frequent, resulting in the addition of an oral phosphodiesterase 4 inhibitor as treatment. Over time, she began to question her treatment goals, and she looked to her family for advice to help her.

After a family meeting with the nurse on her community palliative care team to discuss the goals of care as the list of treatment options became exhausted, the nurse talked with her about "expecting the best but preparing for the worst." Hibaaq listened, but, when asked, she replied that she did not want to think about all of this.

The goals of the palliative care nursing assessment while Hibaaq is continuing treatment are to:

- Assess information needs for treatment decision-making.
- Assess the impact of her current symptoms on her QOL as well as Hibaaq's thoughts about what would make her most comfortable.
- Determine Hibaaq's adherence to her medical plan of care and identify roadblocks and possible remediation for those roadblocks.
- Identify Hibaaq's need for education about her treatment options.
- Address why she does not want to talk about her advance directives.
- Determine the need for a mental health consult for depression and anxiety.
- Assess the need for a chaplain referral to assist with emerging existential issues and threatened faith.

Assessment after Treatment

After treatment, the patient embarks on a journey leading to long-term survival, chronic illness, recurrence or exacerbations, or the terminal phases of the illness. The course of treatment for cancer patients is frequently chemotherapy and/or radiation. Once treatment is completed, the patient enters either remission, long-term survival, or a terminal trajectory. Patients with terminal cancer diagnoses and patients with terminal noncancer diagnoses may, of course, at any time decide to stop all attempts to cure the illness and to initiate a completely palliative plan of care, maximizing comfort and QOL. Sometimes, treatment of an illness during an exacerbation simply does not work. At this point, after treatment is over or the patient stops treatments, the nursing assessment continues to focus on QOL, including patient and family coping.

Patients in this part of their disease trajectory should be assessed frequently to determine if they would be appropriate for hospice; that is, do they meet criteria based on their illness.

The goals of the palliative care nursing assessment after treatment are to:

- Assess the benefits and burdens of all interventions to manage the symptoms remaining from the treatments and/or the disease process.
- Determine the current physical problems that are most distressing to the patient and family to prepare for possible palliative interventions.
- Assess functional status and disease process to determine when a hospice referral is appropriate.
- Assess learning needs about managing problems with the goal of maximizing QOL.
- Assess patient and family strengths, healthy habits, and behaviors to enhance well-being and to prevent problems.

"Survivors" are defined as those patients whose diseases are cured, who go into long remissions, who become chronically ill, or who recover from an exacerbation of a chronic illness. These individuals may require some degree of palliative care for the rest of their lives. Examples of survivors likely to require ongoing palliative care include (1) cancer survivors with graft-versus-host disease (GVHD), irreversible peripheral neuropathies, or structural alterations of the integumentary, gastrointestinal, and genitourinary systems, such as mastectomies, amputations, colostomies, ileostomies, and laryngectomies, and (2) persons with other chronic illnesses who have survived an acute episode and have returned to a chronic phase of their disease process.

Psychosocial issues for survivors include fear of recurrence or exacerbation as well as practical considerations such as insurance and job discrimination. Many patients make major life changes regarding work and relationships because of their illness experiences. These patients live with the ramifications of the disease and its treatment for the rest of their lives, even cancer patients who have met criteria for being cured.

Some patients begin to explore in new ways the spiritual foundations and assumptions of their lives. Often, patients relate that, despite the crisis of an illness and its treatment, the experience resulted in a deepened sense of meaning and gratitude for life.

Physical Assessment after Treatment

The patient is reassessed after treatment to determine the changes that have occurred since previous assessments. Although the focus is on the systems that have been affected and altered by the disease and treatments, assessing the patient from a holistic perspective is even more crucial. Thorough assessment of the residual problems and changes in the patient's body are critical to successful symptom management. Effective management of symptoms with palliative interventions achieves the goal of maximizing the patient's and family's QOL, whether in long-term survival or during the terminal phase. The PPS is a general scale that is widely applied to patients with life-threatening illnesses. Nurses also use functional assessment tools that are developed for patients living with specific chronic or life-threatening illnesses.

In addition to the patient's physical assessment, nurses continue to make periodic observations and inquiries about the health of other family members. Noting changes in family members' health, physical limitations, and physical strengths is important to ascertain any impact on the patient's care and the family's lifestyle.

Psychosocial Assessment after Treatment Ceases

For those patients who are free of disease, palliative care focuses on post-treatment–related symptoms and fears of recurrence. For others, disease progression or recurrence is most often signaled by the appearance of advancing physical symptoms. When this happens, the patient's worst nightmare has been realized. A recurrence or exacerbation is experienced differently than an initial diagnosis because the patient is now a veteran of the patient role and may understand all too well what the recurrence or exacerbation means.

Research suggests that a strong correlation exists between caregiver stress and morbidity.[38] This is especially true of caregiver stress that affects blood pressure and mental health stress responses such as chronic depression. For additional information, refer to Chapter 32, "Supporting Families and Family Caregivers in Palliative Care."

Nurses and other members of the interdisciplinary healthcare team assess the psychosocial domain after treatment when they:

- Revisit the quality versus quantity of life preferences as the patient and family weigh the benefits and burdens of further treatment. Beginning these conversations earlier rather than later in the illness helps to make them less threatening and creates an ongoing dialogue that will help the patient, family, and healthcare providers alike when further treatment becomes futile.
- Evaluate the patient's readiness to discuss a transition in emphasis from curative to comfort care only. The patient often signals his or her readiness by statements such as, "I'm getting tired of spending so much time at the hospital" or "I've had it with all of this." Ask: "What has your physician told you that you can expect now?" or "How do you see your future?"
- Explore readiness to set new goals of treatment: "I know you understand that your illness has not responded to the treatments as we had hoped. I'd like to reexamine your healthcare goals with you."
- Assess for family adaptation to stress and coping.
- Revisit the need for advance directives and changes in code status.
- Reevaluate the need for a discussion about hospice if the patient begins to question the efficacy of treatments and present hospice as the gold standard for end-of-life (EOL) care. A hospice referral should never be made as a gesture indicating that "There is nothing more that we can do for you." The benefits of increased availability of services, such as symptom management, respite opportunities, and bereavement care for the family, should be emphasized.

Spiritual Assessment after Treatment

The main spiritual goal of this phase of illness is to provide the patient and family with a "place to stand" to review the past and look toward the future. This encourages grieving past losses, creating a sense of meaning, and consolidating strengths for the days ahead.

Nurses and other members of the interdisciplinary healthcare team assess the spiritual domain after treatment when they:

- Determine the quality and focus of the patient's and family's hopes for the future. Listen for a transition from hoping for a cure to another kind of hope, such as hope for a remission, hope to live until a special family event occurs, and hope for continuing care for their family when the patient cannot care for them. Observe for any barriers to hope or evidence of hopelessness.[39]
- Listen for comments that suggest a crisis of belief and meaning. For example, at recurrence, a patient may feel abandoned or experience an assault on his or her faith. Questions such as "Why?" and "Where is God?" and "Why are my prayers not being answered?" are very common. Nurses respond to these questions by normalizing them and emphasizing that to question God or one's faith can indicate a vitality of faith, not its absence.
- Assess the patient's and family's use of spiritual practices: "What are you doing to feel calmer and more peaceful?" Determine the need for a chaplain referral if the patient or family are interested and open to such an intervention.
- Inquire about the desire for meaningful rituals, such as communion, special prayers, or anointing. Evaluate the need for consulting with the patient's or family's clergy or a chaplain on the healthcare team.
- Assess the level and quality of community supports: "Who is involved in supporting you and your family now?" and "Do you think you need any additional help?"
- Listen for indicators of spiritual suffering (such as language about unfinished business, regrets, diminished faith, and fears of abandonment) and evidence of relationship discord: "What do you find yourself thinking about now?" and "What are your chief concerns or worries?"
- Assess the need and desire of the patient and family to talk about the meaning of the illness, the patient's declining physical condition, and possible death: "Is there something you would like to talk with me about that you are not asking right now?" and "Would you rather talk somewhere away from your loved ones?"
- Assess the patient's and family's need to review critical life incidents, to allow grieving, and to explore beliefs regarding the afterlife: "What do you believe happens to a person at the time of death?"

Case Study: Hibaaq after Treatment

Hibaaq experienced exacerbations of increasing frequency, having been hospitalized about once per month over the past year. She was extremely fatigued and tired of these hospitalizations and understood her time was drawing short, but she wanted to be able to see the birth of her first grandchild, who was due to arrive in about 6 months. After talking with her family, she decided that she no longer wanted to come to the hospital and that she wanted to pursue a comfort-only plan of care, which comprised hospice care at home. She changed her code status to allow for a natural death at home, but she prayed daily that she would "remain on this Earth to enjoy my family and to meet my grandchild."

The goals of the palliative care nursing assessment after Hibaaq's treatment are to:

- Reevaluate adherence to activities that could maximize her QOL.
- Evaluate appropriateness of interventions that could prevent further crises arising from her COPD.
- Determine the need for relationship-building within the family system to reduce everyone's stress levels.
- Establish Hibaaq's wishes with respect to her advance directives and complete the forms.
- Assess for a referral to hospice.

Assessment during Active Dying

The goal of hospice is to support the terminally ill patient and family wherever they choose to be. Hospice teams provide palliative care in patients' homes, acute care settings, nursing homes, and specially designed inpatient hospice facilities. Unfortunately, many patients die without the support of hospice services.

The goals of a palliative care nursing assessment when the patient is actively dying are to:

- Observe for signs and symptoms of impending death that could be managed aggressively to promote comfort (Table 4.6).
- Determine the primary source of the patient's and family's suffering to plan interventions to provide relief.

Table 4.6 Common physical symptoms by persons who are actively dying

Symptom	Definition
Agitation	Nonpurposeful movements associated with increased anxiety
Anorexia	No interest in eating or drinking
Confusion	Disorientation and lack of orderly thought
Delirium	An acute change in consciousness, cognition, and perceptual disturbances that can fluctuate throughout the day
Dyspnea	Shortness of breath
Fatigue	Overwhelming tiredness
Incontinence	Bladder, bowel
Insomnia	Difficulty sleeping
Mottling	Changes in skin color and temperature due to decreasing circulation that progresses from distal to proximal during the last 2–3 hours of life
Pain	PQRSTU (see Box 4.4)
Restlessness	Uncontrollable increase in motor activity
Skin breakdown	Due to local ischemia secondary to immobility
Terminal secretions	Collection of saliva in the back of the throat that gurgles with each breath

- Identify the primary sources of strength for the patient and family members so that they can be used to provide support.
- Ascertain the patient's and family's need and readiness for teaching about the dying process.
- Look for ways to support the patient and family to enhance meaning during this intense experience.
- Determine whether the family members and friends who are important to the patient have had the opportunity to visit in person or on the telephone, as desired by the patient and family.
- Assess the family to anticipate family members' reactions to the patient's death.
- If not in hospice, assess for appropriateness for referral.

Physical Assessment during Active Dying

Physical assessment during the active dying process is highly focused and is limited to determining the cause of any suffering and identifying sources of comfort. Table 4.7 shows common areas to assess in the last few days of a person's life.

In addition to the patient's physical assessment, nurses monitor the health of other family members to prevent and minimize problems that could compromise their health during this very stressful time. Frequently, assessing the family's need to participate in making the patient comfortable can lead to interventions enabling them to do something to help the patient.

Psychosocial Assessment during Active Dying

Many people believe that the transition from life to death is as sacred as the transition experienced at birth. Keeping this in mind, nurses can help to create a safe environment in which patients and families are supported in their relationships and the creation of meaningful moments together. The patient may also still be reviewing his or her life. Common psychosocial characteristics of the person who is actively dying include social withdrawal, decreased attention span, and decreasing ability to concentrate, all culminating in a gradual loss of consciousness. Spiritual experiences such as visions and visitations from deceased relatives or spiritual/religious figures are often viewed as normal and transcendent at this stage of life in those with strong spiritual beliefs. Nurses avoid the tendency to medicalize transcendent experiences and view them as nonaberrant, positive, and an opportunity for making meaning.

During active dying, nurses and other members of the interdisciplinary healthcare team assess the psychosocial domain when they:

- Assess the patient's reports of seeing deceased loved ones or visions as normal and not as evidence of confusion or other mental health problems and determine the need for a behavioral health consult to distinguish such experiences from delirium.
- Evaluate for the need to support communication among the patient, family members, and close friends, and the need for reminiscing, story-telling, and other familiar ways of relating to each other—for example, through humor and singing.[40,41]
- Assess the patient's and family's need and readiness for continued education about death and dying, particularly children (Box 4.7).
- Evaluate for the need and readiness of family members to learn that continued touching and talking to the patient is appropriate, even if the patient is unconscious.
- Assess for need and readiness of the family members to learn to give permission to the patient to let go and to provide reassurance that the family will remain intact and will learn to deal effectively with the patient's absence.
- Observe family members for evidence of poor coping and for the need to make referrals for additional support. See Box 4.8 for risk factors for complicated bereavement in family members.
- Assess the family members for the need and readiness to learn about organizing visitation shifts that rotate in the face of lengthy and exhausting vigils at the bedside.
- Revisit any complementary and alternative therapies that the family might find effective.[42]

Spiritual Assessment during Active Dying

When the patient enters the phase of active dying, spiritual realities often increase in significance. Persons with life-threatening illnesses who participate in spiritual rituals experience feelings of higher existential well-being and less subsequent spiritual strain.[43] The goals of spiritual care during active dying are to:

- Facilitate any unfinished business among the patient and significant others, such as discussions with others to express love, regret, forgiveness, and gratitude.
- Promote the integrity of the dying person by honoring his or her life. One way to do this is by encouraging reminiscence at the bedside of the patient, recalling the "gifts" the patient bestowed on the family—that is, his or her legacy of values and qualities passed on to survivors.

Table 4.7 Assessment during active dying

General	*Location*	Is the home the best place for the patient to die? Has the family thought about their comfort in living in the house after their loved one dies there? Is the room too hot or too cold for the patient and for the family in the room?
	Symptoms	Are pain and other symptoms well controlled? Would massage, body energy work, or other complementary therapies add to patient's comfort?
	Family	Is everyone present who is supposed to be there? Are family members capable & comfortable with continuing to provide physical care for the patient? Are family members getting enough sleep and rest to maintain their own health? Are additional resources needed to support the family? Would the patient want the family pet in the room or on the bed?
	Spirit	Does the patient want a special member of the clergy present? Are they available to be here for the patient and the family? Are there any spiritual or cultural rituals to be done before or immediately after death?
	Help	Does the family know whom to call on a 24-hour basis for advice and support? Does the family know not to call for emergency medical services when the patient dies?
Head & neck	*Mind*	How important is level of alertness versus control of pain and anxiety which may cause sedation?
	Vision	What objects and people at the bedside provide comfort when seen by the patient? Family photos? Children's drawings? Special objects? Pets? Loved ones sitting nearby? What degree of lighting does the patient prefer? Does darkness increase anxiety? Would scented candles provide solace?
	Hearing	What sounds most comfort the patient? Music? Family chatting nearby? The TV or radio on in the background? Would music thanatology be of comfort? Someone reading to him or her? Silence?
	Smell	What scents does the patient enjoy? Would aromatic lotions be soothing? Are there clothes of a person whose scent would be of comfort? Does the patient have favorite colognes or perfumes? If on oxygen, would humidification be of comfort?
	Taste	What are the patient's favorite flavors? Would mouth care to relieve dryness be more acceptable with fruit punch, apple juice, beer, or coffee?
	Mouth	Does the family/caregiver understand how to provide good, frequent mouth and lip care, particularly if the patient is a mouth-breather?
	Face	Does the patient receive comfort from face and head massage or a facial with aromatic salves? Does a fan blowing on the face relieve feelings of air hunger?
Shoulders & arms	*Mechanics*	Do the caregivers understand good body alignment and several ways to position the patient comfortably? Are they following good body mechanics when repositioning the patient?
	Soothing	Would applying aromatic lotion to hands and arms comfort the patient and give family members something meaningful to do?
Chest, back, & spine	*Lungs*	Is the patient at high risk for death rales? Is there a scopolamine patch or other meds in the home for immediate use if noisy respirations begin? Would oxygen help the patient breathe easier? Or a fan pointed at the patient's face?
	Heart	If patient is at home, is the family prepared for the moment of death? For example, do they know NOT to call 911? Do they have a neighbor close by to come and be with them until a healthcare provider arrives?
	Back & spine	Are pain patches in place or do they need to be changed? Does the family know how to boost the patient back up in bed when they slide down? Does the family understand how and when to turn the patient for comfort? Does the family know how to make an occupied bed, using good body mechanics?
Legs & feet	*Circulation*	Are family members interested/concerned with learning the assessment technique of feeling the feet and limbs for coolness and examining for mottling as they progress slowly from the periphery to the center of the body during the last few hours of life?
	Soothing	Would applying aromatic lotion to feet and legs comfort the patient and give family members something meaningful to do?
Abdomen	*Bowels*	If the patient is incontinent of stool, are family members comfortable and know how to provide personal hygiene? Do family members know how to use protective pads, adult diapers, pull sheets to keep the patient clean? If stools are frequent, can antidiarrheals be given? Ostomy care?
	Skin	Are protective ointments needed to decrease skin breakdown if the incontinence is frequent? Are pressure points up off of the bed?
Pelvis	*Urine*	If incontinence is present, would inserting a Foley catheter prevent skin irritation and conserve the patient's and family's energies? Is the family comfortable doing this? Are others available to insert the catheter?

- ◆ Assist the patient and family in extracting meaning from the dying experience.
- ◆ Provide sensitive comfort by being present and listening, or determine the patient's and family's need for privacy.
- ◆ Provide information regarding hospice, bereavement support groups, or counseling if indicated.

During active dying, nurses and other members of the interdisciplinary healthcare team assess the spiritual domain when they:

- ◆ Determine the need for different or more frequent visits by the patient's or family's spiritual support person: "Is there anyone I can call to be with you now?" and "Are there any meaningful activities or rituals you want to do?"
- ◆ Inquire about dreams, visions, or unusual experiences such as seeing angels or persons who have died, reports of needing to go home, or awaiting the arrival of a bus or a train, to normalize these if they are disclosed. Ask if these experiences are sources of comfort or fear and encourage further discussion, if appropriate.
- ◆ Assess for ability to maintain hope by asking, "What are you hoping for now?" reassuring the patient and family that they can be hopeful and still acknowledge that death is imminent and that moving toward a transcendent hope is vital. Evaluate for the need to reinforce that although the focus of hope may have been on cure, remission, or an extension of time earlier in the disease trajectory, now hope may be focused on an afterlife, the relief of suffering, or the idea of living on in loved ones' memories.
- ◆ Listen for and solicit comments regarding the efficacy of spiritual practices. For instance, if the patient is a person who prays, ask, "Are your prayers bringing you comfort and peace?"
- ◆ Assess for expressions of fear, panic attacks, or an increase in physical symptoms such as restlessness, agitation, pain, or shortness of breath that may indicate intense spiritual distress. Evaluate for the need for a chaplain's intervention to provide spiritual comfort and to assist the patient in reaching peace, possibly reducing the need for medications.
- ◆ Determine the need and desire of the patient and family to engage in forgiveness, to express feelings to one another, and to say their good-byes. Assess the need to facilitate phone conversations if the family member or friend cannot be present physically and to educate the family to hold the phone up to the dying patient's ear to hear the voice at the other end, even if the patient cannot move or is comatose.
- ◆ Assess for a prolonged dying process that may indicate the patient is having difficulty letting go, perhaps due to some unfinished business, an unsaid good-bye, or fears related to dying. Explore with the patient and family what these issues might be and assess for the need for a chaplaincy referral.
- ◆ Assess for readiness of the family to celebrate the life of the loved one by acknowledging his or her contributions to family members, close friends, and the community.
- ◆ Explore the need and desire for additional comfort measures in the environment, such as soothing music, devotional readings, gazing out a window at nature, or increased quiet.

Box 4.7 Common Responses of Children to Serious Illness in the Family

- ◆ Magical thinking that results in feelings of guilt, for example, "I once told Mommy I wished she were dead."
- ◆ Fears of abandonment, especially in younger children.
- ◆ Fears of contracting the disease.
- ◆ Anger, withdrawal, being uncooperative, especially in adolescents.
- ◆ Acting-out behavior with lack of usual attention.
- ◆ Frustrations with an altered lifestyle because of decreased financial resources, less family fun activities because of the ill person's inability to participate, interruptions in schedule.
- ◆ Inability to concentrate and focus, especially regarding schoolwork.
- ◆ Identify family communication ground rules to seek to improve communication among family members: "Is it OK if we discuss this subject with you and your family?"
- ◆ Help the patient and family explore the benefits and burdens of various treatment options when making decisions about the plan of care.
- ◆ Assess parental readiness to assist children with their adaptation needs: "How do you plan to tell your children?"
- ◆ Assess the coping of children within the family by being aware of their fears and concerns.

Box 4.8 Risk Factors for Complicated Bereavement in Family Members

- ◆ Absence of helpful cultural and/or religious beliefs.
- ◆ Age of the patient and the surviving loved ones, developmental phases of the patient and family members.
- ◆ Anticipated situational stressors, such as loss of income, financial strain, lack of confidence in assuming some of the patient's usual responsibilities.
- ◆ Concurrent life crises.
- ◆ Determine the patient's and family's need and interest for education about death and dying.
- ◆ Extreme anger or anxiety.
- ◆ History of mental illness or substance abuse.
- ◆ History of other recent or difficult past losses.
- ◆ Illnesses among other family members.
- ◆ Limited support within the family's circle or community.
- ◆ Marked dependence on the patient.
- ◆ Special bereavement needs of children in the family.
- ◆ The patient's dying process is difficult, as can be indicated by poorly controlled symptoms of pain, shortness of breath, agitation, delirium, or anxiety.
- ◆ Unresolved grief from prior losses.

Box 4.9 Assessing for Funeral Plans and Preferences

- A consumer-oriented guide to funeral planning is available at http://www.funeral-help.com that includes funeral planning software for purchase.
- Assess for a referral to hospice for EOL care if the death of the patient might be anticipated within the year. Ask other members of the interdisciplinary healthcare team: "Would it surprise you if this person would die within the year?"
- Assess the patient's and the family's readiness to discuss funeral preferences and plans and desired disposition of the body.
- Determine the need and desire for reconciliation: "Are there people with whom you want or need to speak about anything?" and "Do you find yourself having any regrets?"
- Determine the patient's and family's readiness to talk about the most meaningful, celebratory occurrences in life to foster integrity, life review, and a sense of meaning: For example, "How did you meet your spouse?," "Were your children all born here?," and "Where did you and your other half like to vacation?"
- Does the patient want to make his or her wishes known regarding the type of service, or will the family decide these details? For example: clothes to be buried in, favorite songs to be sung or played, poems to be read, casket or urn selection, open or closed casket.
- Has the decision been made regarding a burial or disposition of the ashes? For example: the cemetery, the plot for burial or inurnment, the mausoleum crypt, the columbarium niche, or the location for scattering ashes.
- Has the patient and/or family decided about the disposition of the body? For example: organ, eye, and/or tissue donation; autopsy; in-earth burial (above ground or below ground); cremation; and/or total body donation to a medical school.
- Has the patient and/or family selected a funeral home or a funeral and memorial society?

- Ask the family about their anticipated needs and preferences at the time of death: "Is there anyone you will want us to call for you?," "What can the healthcare team do to be most supportive?," "Are there specific practices regarding the care of the body that you want the team to carry out?" See Box 4.9 for ways to assess for funeral plans and preferences.

Case Study: Hibaaq's Death

Granddaughter Shamsi arrived a bit later than Hibaaq expected. The tears in the new grandmother's eyes rained down across the mask that was helping Hibaaq breathe. As her breathing changed, Hibaaq's family kept vigil. The hospice nurse suggested that the family continue to talk to Hibaaq as death drew closer. Liban asked if the sounds in her throat were bothering her. The hospice nurse continued to treat Hibaaq's symptoms as she slipped away, having achieved her goal of meeting her granddaughter. The family wept when the hospice nurse reported to them that Hibaaq was gone.

The goals of the palliative care nursing assessment during Hibaaq's active dying phase are to:

- Evaluate Hibaaq and her family frequently for comfort including the need for extra chairs, the desire for coffee, and reminders to take breaks from time to time.
- Assess the environment for factors that are calm and soothing.
- Be vigilant for adherence to the patient's religious and cultural preferences in spite of the absence of written advance directives.
- Determine the need to resolve conflict about EOL care preferences and measures that could be implemented to improve patient and family outcomes.
- Discover the need to educate the family on the appropriate response to changes in a dying loved one's status.
- Inquire about the family's readiness to learn about the hospice's community grief program.
- Determine one's own needs and the staff need for support after caring for a patient for a long time and who has now died.

Conclusion: Principles of Patient and Family Assessment

A comprehensive palliative care nursing assessment of the patient and family occurs throughout the trajectory of the illness and is a holistic view that includes the physical, psychosocial, and spiritual domains. Patient and family assessment provides the foundation for mutual goal setting, devising a plan of care, implementing interventions, and evaluating the effectiveness of care. Reassessments are done throughout the patient's illness, looking for changes from previous assessments to ensure that QOL is maximized in all domains. Box 4.10 offers a best-practice tip for assessing symptoms.

Maximizing QOL for patients and families is a process. It is a journey that the nurse and all members of the interdisciplinary healthcare team travel alongside of the patient and family. The palliative care nurse understands that, above all and irrespective of the phase or focus of the assessment, two of the most important assessment questions that the nurse can ask the patient and family are "What is your greatest concern?" and "How can I be of help?"

Box 4.10 Best-Practice Tip

Clinicians may find the use of an abbreviated symptom assessment form helpful to track the efficacy of palliative care interventions. Whereas pain is usually plotted along the familiar 0–10 scale, other symptoms such as nausea, vomiting, diarrhea, constipation, fatigue, anxiety, and depression can be quickly evaluated on a flow sheet as mild, moderate, or severe or using a symptomatology scale. Also, the Palliative Performance Scale (PPS) can provide a numerical evaluation of functionality that is quick to record and compare. These kinds of tools assist in interdisciplinary evaluation of symptoms and patient status without requiring paging through lengthy progress notes. In this way, treatment can be highly individualized and evidence-based.

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CHAPTER 5

Communication in Palliative Care

An Essential Competency for Nurses

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Key Points

- The foundation of quality palliative care is effective communication that assures an individualized, respectful approach to care, from diagnosis to death, with regard to values, preferences, and beliefs.
- The art of nursing communication involves the therapeutic use of self, presence, silence, and listening to facilitate a patient- and family-centered process.
- The science of communication is a learned skill that establishes the nurse–patient relationship, comprised of 20% verbal and 80% nonverbal characteristics.
- Essential nursing communication includes gathering and imparting information and providing support and reassurance, as dictated by the individual needs of patients and families.
- Nurses have an essential role in advance care planning (ACP). Other roles include delivery of bad news and poor prognosis or discussing the transition to hospice and palliative care.

Introduction

The art and science of palliative nursing is founded on communication.[1] Nurses have an important role in patient care, particularly in palliative care communication.[2] As the most trusted member of the healthcare team,[3] they play an essential nursing role in advocating for and implementing the patient's wishes and preferences and communicating these to family members and other healthcare providers. Often, a nurse is the patient's first healthcare contact and spends the most time with the patient at the bedside. Nurses are essential to team work in promoting optimal communication among the team, patient, and family.

The American Nurses Association (ANA) *Nursing Scope and Standards of Practice* communication standard states that the nurse "communicates effectively in all areas of practice."[4 (p.71)] To do so, the nurse assesses his or her own communication skills and effectiveness that demonstrate caring, respect, deep listening, authenticity, and trust. This also includes the nurse's responsibility to assess communication ability, utilize alternate strategies for difficulties, convey accurate information, maintain interprofessional team communication, and demonstrate continuous improvement of communication skills.[4]

The ANA *Code of Ethics* delineates the nurse's obligation to promote patient self-determination through the assessment of patient understanding of information and the implications of all potential decisions. Nurses support patient autonomy through patient decision-making, particularly around difficult decisions.[5] In particular, they assist patients to define their goals and wishes as well as to express their cultural and religious practices and preferences.

Case Study: Marita

Marita worked as a registered nurse on a psychiatric floor. She had many patients with depression as well as congestive heart failure, pulmonary disease, diabetes, cancer, and renal failure. She enjoyed her work as she felt her expertise was working with patients and families to decide on goals of care as patients are discharged from the floor. One patient frequently admitted was Frances Leary, a 51-year-old woman with depression, diabetes, heart failure, renal failure, and hepatitis C. At first, Frances was very stoic about her care and told everyone she was fine. Marita was consistent in providing therapeutic presence during each admission, treating Ms. Leary with respect. One day, while helping Ms. Leary with dressing, she asked, "Ms. Leary, how do you feel about being in the hospital?" Ms. Leary stated that she did not like to be in the hospital, but felt she needed to fight for her family. When Marita asked her about what she would prefer to do, Ms. Leary stated she wanted care at home so she did not have to come back. Marita learned she was separated from her husband and had a daughter and a son. However, all of the family members were involved with her care.

Overview

Although communication seems fairly straightforward, it is actually a complex, continual transactional process that occurs between persons by which information, feelings, and meaning are conveyed through verbal and nonverbal messages. As viewed by multiple goals theory, communication interaction is seen as the exchange of ideas around a task, as well as the exchange of ideas around a relationship. In essence, multiple goals theory describes every message as possessing two levels of meaning: the content level and the relationship level.

In professional contexts, these can be referred to as the *task* and *relationship* levels.[6,7] Message content generally concerns the *tasks* of communication—for example, instructing, diagnosing, managing, directing, encouraging, supporting, and so forth. *Relationship* refers both to how people interpret the content of messages and how they understand their shared connection. For example, if a nurse asks a patient, "What is your pain level today?" the content is obviously an inquiry designed to obtain information about the patient's pain. Still, the relationship level of meaning is determined by how these words are spoken. If the nurse is glancing at paperwork or working with medical equipment while she asks this question and no eye contact is made, or if she is standing in the hallway rather than at the bedside, the patient will likely interpret this as a matter of routine communication rather than a genuine inquiry. As a result, no relational components are developed within the exchange.

While the content level of a message is conveyed by the words themselves, the relational level generally is manifested by nonverbal communication. *Nonverbal communication* includes physical appearance and grooming, both of which influence perception. *Artifacts*, the presence of physical objects and the environmental setting, can be barriers to developing relationships with patients and families. These objects include bedrails, bedside tables, and other medical equipment that reduce the emotional connection during conversation. A nurse sitting for a short time at the bedside versus standing at a distance and separated by bedrails can greatly impact communication. *Vocalics*, the variety of ways that words are spoken, including volume, pitch, accent, rate of speech, use of pauses, and tone, also are part of nonverbal communication. The way the voice is used communicates loudly on a relational level. For example, speaking loudly to an elderly patient who has good hearing can be condescending and can distance the nurse from the patient. *Proxemics*, the way space and distance is used during communication, and whether or not it is respected and acknowledged during nursing work, can impact relational communication. Finally, *haptics*, or the use of touch, can be task-related but can also convey relational messages of warmth and caring.

Within undergraduate nursing education, there is little education specific to communication, let alone in palliative care. Yet nurses rank communication as the most important competency.[8] Although nurses are now exposed to care along the disease trajectory, this phenomenon continues today as nurses still feel unprepared in communication skills.[9] Nurses fear saying the wrong thing, causing emotional distress or sadness that they feel unequipped to manage, showing emotion with patients and families, or not having permission from the clinical team to discuss serious matters.[10–13]

Nursing communication is focused on the patient as the person who experiences the illness or condition, as well as being focused on the family.[14–16] Opportunities for communication exist throughout nursing care delivery, such as during patient care including task-related care, personal care, illness education, bad news delivery, assessment of spiritual and religious concerns, in response to physical and psychological distress, and within interdisciplinary collaboration.[11,17] There are a myriad of settings beyond the home or the hospital, including wherever care occurs: rehabilitation facilities, office-based clinics, long-term care facilities, veterans' facilities, correctional facilities, homeless shelters, group homes, and mental health settings. Without effective communication, the patient's experience of suffering is unknown, and effective symptom control is impossible.[18,19]

Box 5.1 Communication Behaviors Valued by Patients and Families

- Being present and being silent
- Being in the moment
- Knowing and being comfortable with oneself
- Knowing the other person
- Connecting
- Affirming and valuing
- Acknowledging vulnerability
- Utilizing intuition
- Empathizing and willing to be vulnerable
- Providing serenity and silence

Source: References 52, 67.

Effective Communication

Communication is a central aspect of patient- and family-centered care whereby the needs of the patient and family dictate care.[20] Communication promotes many critical aspects of care: information sharing; active listening; identification of values, goals, and health care preferences; and decision-making, and it facilitates support and collaboration.[21] Effective communication, as viewed by seriously ill patients and their families, primarily consists of providing accurate information in a sensitive, simple, and straightforward manner using plain language.

Good communication allows for optimal palliative care because it is the basis of the relationship.[1] Communication provides a basis for a strong nurse–patient relationship and a therapeutic basis for the care.[2] Specific nursing behaviors focus on the promotion of information-sharing, disclosure, reassurance, presence, facilitation, and dignity.[22–24] Indeed, emotional intelligence may promote more effective communication. Specific abilities include (1) the correct identification of emotions in oneself and others, (2) the use of emotions to facilitate reasoning, (3) understanding emotions, and (4) managing emotions.[25]

Nurse interactions have been described within the following categories: supporting, caring, collaborating, reassuring, fostering hope, and advocating for the patient.[23] Research speaks to the various aspects of communication: active listening, presence, eliciting preferences, and facilitating communication choices.[26] The establishment of trust, continuity, and understanding fosters good relationships[26]; and creating a patient-centered approach facilitates more effective communication.[27] Box 5.1 reviews valued communication behaviors.

The Role of the Nurse in Palliative Care

Nurses are often the first health provider to meet with and identify issues for patients with life-threatening illness. They create a therapeutic relationship and accompany the patient through the illness journey with their constant presence, and they may be best situated to learn the patient's hopes, worries, dreams, regrets, and fears of being a burden.[1,28,29] Moreover, they can advocate for the patient's values, preferences, and wishes.[30] To be effective, nurses need education and empowerment to initiate these discussions.

Honesty and hope conveyed by healthcare providers has been revealed within the literature to be important to patients and families. Focusing on quality of life (QOL) offers hope and meaning to the patient, leaving open the possibility of "miracles" while simultaneously assisting the patient to prepare for losses.[31] Honesty can be achieved through open dialogue and determining patient readiness to discuss serious illness, death, and/or dying.[32] Additionally, discussing outcomes other than cure, such as improved functional status or independence in care needs, assists in focusing the care on the current situation.

With the relief of suffering as the basis of nursing, all nurses practice some aspects of palliative care.[4,33,34] Various communication modalities promote relief of physical, emotional, spiritual, and psychological distress: availability, presence, empathy, respect, listening and talking, eye contact, smile, warm voice tone, and words of comfort, caring, encouragement, and even humor, as well as the use of touch.[35] The heart of this is therapeutic presence: attending to suffering, affirming the patient's self-worth and dignity, decreasing isolation, facilitating identification and clarification of treatment goals, embracing advocacy, and enhancing holistic care.[36]

Nurse characteristics preferred by patients and family and delineated in research cross both verbal and nonverbal realms. One study described satisfactory patient communication as compassionate, responsive, and dedicated, while unsatisfactory patient communication was described as sparse, conflicted, contradictory, and increasing only when things were close to the end.[37] Overall, it appears that patients and families want consistent and routine communication with a compassionate presence.[37] Required communication skills include effective listening, appropriate nonverbal communication, counseling skills, empathy, and supportiveness.[38] The most beneficial nurse behaviors for families are (1) keeping family informed, (2) providing assurance, (3) being a compassionate presence, (4) facilitating final acts, and (5) honoring dignity.[26] Another study categorized nurses' communication encompassing skills that explore patient concerns, the provision of support, enhancing disclosure, educational preparation, and referral for further counselling, as necessary.[22] Essentially, facilitative styles that reflect the therapeutic use of self and patient-centered care are more beneficial than directive styles.[27]

Communication with patients has several aspects. The first is day-to-day interactions focusing on nursing tasks. This occurs in simple communication such as small talk or in providing information on basic treatment issues, medication schedules, activities of daily living, or personal care. Another component includes the nursing process and assessment of treatments. The nurse approaches the patient in an open manner to assess the physical, psychological, spiritual, and emotional aspects of care and treatment. Within this process, the nurses allow the patient to determine treatment effectiveness. The third and most complex component of communication occurs in the existential realm. This is attending to the patient's deepest sense of self. Communication at this level is sensitive and often nuanced because the existential aspects of end of life include disclosure, searching for meaning, and suffering.[19] Exploration at this level can help a patient live with a life-threatening illness, achieving both better QOL and psychological healing.[39]

Across the palliative care spectrum, communication occurs at critical junctures. Depending on the diagnosis or condition of the patient, such communication may occur over a long or a short period of time. Since 80–90% of patients who die have a chronic illness, there are usually many opportunities for communication to occur.[40] Within the nurse–patient relationship, Perrin speaks about three stages: introductory, middle, and termination (see Table 5.1).[41] The introductory phase of communication occurs when the nurse and the patient learn about each other's styles. The middle phase involves establishing a working relationship in which the work of nursing is done, such as pain and symptom management, and discussions are held about the meaning of life, along with discussions of legacy and family closure. The third and final phase is termination, in which the nurse and the patient say goodbye to each other either because the patient or nurse is leaving the system or the patient is dying.

The initial communication or introductory phase starts at diagnosis with the introduction of the nurse as a member of the care team. During this period, the nurse assesses the patient's learning styles and information needs, and the patient determines the nurse's style.[41] The tasks for the nurse include exploring the patient's understanding of his or her illness, eliciting personality and coping styles, and identifying existing documents related to the delegation of surrogate decision-makers, advance directives, or out-of-hospital medical orders for life-sustaining treatments. Assessing learning style includes discerning the patient's ability to learn and understand the seriousness of the illness. These abilities vary according

Table 5.1 Stages of the nurse–patient relationship

Stage[41]	**Initial or Introductory Phase**	**Working Phase**	**Termination Phase**
Nurse Tasks	1. Exploring patient/family understanding of illness. 2. Determining personality, coping and learning styles. 3. Eliciting presence of advance care planning.	1. Monitoring patient response to illness. 2. Providing clinical care. 3. Delivering treatment. 4. Offering illness/treatment	1. Saying goodbye. 2. Telling the patient what he/she meant to them or taught them. 3. Assisting with the transition.
Patient Tasks	Establishing trust and understanding with the nurse.	1. Establishing care plan in collaboration with team. 2. Participating in care. 3. Providing information on response to therapy.	1. Saying goodbye. 2. Showing appreciation to nurse and other staff. 3. Articulating needs with transition.

Table 5.2 Translation of medical language to lay language

Concept	Medical Language	Lay Language
Surrogate decision maker	You assign a durable power of attorney	You would assign someone
Articulate values and preferences	You may state your values and preferences	You may want to tell us what you want
Resuscitation	We would perform chest compressions and intubation	Your chest would be squeezed and a tube would be inserted into your throat.

to the age and cognitive development of the patient, as well as literacy, numeracy (capacity for numerical thought and expression), and native language. For children and some older adults, the family or support unit is primarily involved in both the information gathering process and ongoing communication with the health team.

The next phase is the working phase, which often extends over the course of the illness. Supportive care focuses on lifestyle adaptation to a serious, life-threatening illness, including providing information on the condition, treatment, and management (pharmacological, nonpharmacological, and interventional).[39] The patient and family establish trust with the nurse, who provides presence, emotional support, and reassurance.[39,41] The nurse has insight into patient and family coping and articulates their concerns or perceptions of care. At this time, according to Pierce, the nurse fulfils three critical communication tasks in end-of-life (EOL) care: (1) creating an environment conducive to communication, (2) easing interactions between physician and patient, and (3) facilitating interaction between family and patient.[42] Therefore, difficult discussions of bad news require nursing presence; the nurse is able to offer his or her perspectives of care and facilitate follow-up using language and shared information that was similar to that used in initial discussions.

As the patient enters the stage of advanced illness, the termination phase commences. It should be noted that termination may also occur if the patient changes practice settings or the nurse transitions to another position. At this time, the nurse offers continued presence and reassurance in monitoring comfort and providing intensive caring to both the patient and family.[43] Communication between the nurse and the patient and family focuses on support of decision-making, assurance of comfort, relief from pain and symptoms, information about the dying process, and solace in anticipatory grieving. The family caregiver's burden is often overlooked, but it is a major aspect of the illness experience.[44] It is hoped that the nurse and the patient are able to come to some closure as the patient dies. Immediately following the death, the nurse has a critical role in providing family support with the goal of promoting a healthy grief and bereavement process as much as possible.

Communication Barriers

Communication barriers exist for the patient, the family, and the nurse. For the patient, psychological barriers such as anger, fear, sadness, and helplessness prevent communication. Patients may feel that any discussion will cause too much distress for themselves and/or their families. For some patients, communication is not an area of comfort or value, so they may have little interest in processing feelings or information. Communication difficulties are common when patients are culturally and linguistically diverse from the health team.[45] Educational level and health literacy prevent comprehensive communication, particularly when medical language and jargon are used. See Table 5.2 for translations of common palliative care medical terms into lay language. Depending on socioeconomic status, patients may be overwhelmed with insurance issues, appointments, tests, procedures, treatments, and their cost implications. Patients may engage in a bit of "magical thinking"—that is, the fear that talking about something about their health may make it happen. The physical surroundings of the care environment have been noted to be potential communication barriers.[46] This includes noise, distractions, and lack of privacy, appropriate lighting, and seating. Finally, physical limitations such as cognitive, vision, hearing, and speech impairments, as well as pain or exhaustion, may limit communication.[47]

Families or caregivers share many of these same barriers.[48] They face dilemmas when talking about the patient's life-limiting illness, and this often inhibits information exchange.[49] Families may not understand the full extent of illness and may not know what to discuss. Moreover, families may find it too painful to talk about the advanced state of their loved one's illness because such discussion triggers anticipatory grief and loss. In order to maintain hope, families tend to overestimate the possibility of cure. They also fear future regrets if they do not pursue or demand further curative treatment. Last, it is not uncommon for family members to have little knowledge of the patient's preferences for types of care. Therefore, their ability to fully participate in decision-making in the context of the patient's preferences is limited.[50] Nurses must attend to the family caregivers to assure quality care of the patient.[51]

Circumstantial barriers exist as well.[52] Time is always an issue, in terms of attending to a patient or the time available to deeply discuss an issue. The scheduling of patients using layered appointments and tests may allow for little reflective time or time for meaningful discussion.[46] Changes in the patient's condition may prevent full discussion of details, considerations, or future treatment. Barriers to goals-of-care discussions include family members' or patients' difficulty in accepting a poor prognosis, difficulty understanding the limitations and complications of treatments, disagreement among family members, and patients' incapacity to make decisions.[53] All of this may be affected by lack of privacy in care settings such as open treatment suites for chemotherapy, renal care, heart failure, or in urgent care settings. Families may be uninformed and receiving mixed messages. Additionally, situations where information exchange must occur by telephone prevent the nurse from "reading" the family's nonverbal communication.

Nursing communication barriers include personal, professional, and legal concerns. Nurses may have difficulty or discomfort with communication due to personality, cultural norms, struggles of unresolved grief, fear of their own mortality, or fear of being emotional in front of a patient.[13,54,55] A lack of education and training, difficulty in prognostication, and perceived reluctance of patient or family all contribute to nurse communication barriers.[56,57] New nurses worry that bringing up issues related to death and dying will cause too much emotional distress to the patient and family.[54,55,57]Alternatively, they may worry about their scope of practice or authority to initiate such conversations. Some nurses are concerned that talking about palliative issues will result in patient and family conflict.[58] Finally, even though communication and information-sharing is part of the scope of practice and advocacy for both registered nurses (RNs) and advanced practice registered nurses (APRNs), many nurses feel discomfort with EOL communication and focus on maintaining hope instead of talking about prognosis.[59]

Consequently, nurses may employ avoidance behaviors regarding communication. A nurse may focus more on the biomedical aspects, particularly using technical medical jargon, and thereby avoid any elicitation of or response to a patient's thoughts and feelings.[23] Or a nurse may focus only on the present time, preventing the patient from expressing previous concerns. For example, rather than listening to the patient share concerns, the nurse may stop the conversation by providing false reassurance such as, "It will be okay now," or dismissing the emotion with a sentence such as, "Don't worry about that, it will just make you more anxious." Another way of avoiding discussion is to change the focus or the subject. For example, if the patient says, "I am worried about my family," the nurse may divert the conversation by saying, "So, how is your nausea?" Sometimes the nurse may interrupt the conversation by offering advice: "Of course, you will get over this in time. It won't last for too long." Another avoidance technique is responding to a patient's expressed difficulties by stating, "Clearly, you need to talk to the social worker about your issues."[60] Or, "it is not my role to discuss this." Finally, nurses and physicians may collude with patients in avoiding any discussions of death and dying, thus preventing information-sharing with the patient.[57,61,62]

The COMFORT Model: A Model for Effective Communication

A novel communication training curriculum named COMFORT, an acronym that identifies the basic principles of nurse communication, is offered as a communication framework.[52,63] Built from evidence-based research in hospice and palliative care settings, the COMFORT curriculum teaches nurses to focus concomitantly on task and relational communication as a way of improving communication and resolving communication challenges. COMFORT is an acronym that stands for the seven basic principles of palliative care communication (C-Communication, O-Orientation and options, M-Mindful communication, F-Family caregivers, O-Openings, R-Relating, T-Team). The curriculum teaches nurses how to provide life-altering news, assess patient/family health literacy needs, practice mindful communication, acknowledge family caregivers, and address communication openings and goals. COMFORT is designed to assist nurses with the practice of biopsychosocial and patient-centered communication. The framework is not a linear guide, an algorithm, a protocol, or a rubric for sequential implementation by nurses but rather a set of holistic principles that can be used concurrently and reflectively in the care of patients/families with life-limiting illness.

Information Needs of Patients and Families

To best provide supportive care to patients and families, it is necessary to understand their information and communication needs. Patients require information about treatment options, management of symptoms, support from family and friends, fulfilment of family or cultural expectations, attaining meaning, and maintaining dignity and control. Correspondingly, the communication needs for the patient include disease specifics, rationale for care, being listened to, and the opportunity to participate in important discussions. The role of the nurse is to assess the patient's knowledge and concerns in these areas, offer reinforcement of health information, and facilitate information exchange with the rest of the care team. The nurse also guides the patient in understanding the care plan, clarifies team responsibility for specific aspects of care, and provides support in the process.[64,65]

In order for full participation in the patient's care, family communication is essential. The communication needs of the family and other caregivers depend on their role in the family system, age, decision-making ability, and other rules within and specific to the family. Family caregivers/members are not always aware of the information they might need, may avoid relevant information, and may not express their information needs.[66] The most frequently reported information need among patients and families receiving palliative care is about pain management. Families also need to understand how the interdisciplinary team works, including the individual team members involved in care, their roles in the plan of care, what influences the plan of care, and the site of care.[67]

Nurses are information providers and communication facilitators, educating patient and family about illness and procedures, challenging family members to consider the consequences of treatment, and encouraging awareness about a patient's decline over time.[68] As an information provider and communication facilitator, the nurse provides reassurance of the patient's comfort, support in coping with the patient's condition, explanations of the evolving care plan, and delineation of the current aspect of clinical care. Moreover, families may be very involved in care but have multiple home and work obligations. Therefore, it may be a challenge for family members to participate directly in meetings at the bedside, which may necessitate frequent nursing updates about care. Finally, families may experience a high level of stress because of their need for constant updates of information.[69] The nurse has a major role in acknowledging and validating the family's stress and emotions. Families who are able to talk about the disease are able to support a patient's preferences for care, navigate the practical demands of care, and come to terms with difficult issues.[49]

Conflict in palliative care arises from mismatched expectations and suboptimal communication.[70] When family members begin to have concerns about the patient's quality of care, this is an indication that they are insufficiently prepared for the patient's death and/or are having difficulty understanding and accepting the prognosis.[70] A common circumstance occurs when either the family member or the patient requests that the other party not be informed about the extent of the seriousness of the situation. If the family is protecting the patient, the nurse should explore the family's reason for withholding information. Such requests may include spiritual beliefs, cultural issues, fear of death, fear that the patient will lose hope and give up, or discomfort with any such discussions. Each concern requires a different approach. If there is a spiritual or cultural issue, the nurse must explore the family's spiritual dimension and cultural mores.[71–73] If the family states they are fearful, the nurse can explain that most patients want to know their diagnosis so that they can participate in life closure activities and determine how to spend their final days. Most importantly, the nurse must assess the patient and determine whether he or she wants to know health information and how much health information he or she wants to know. Finally, in this situation, the nurse must attend to his or her own integrity. The response to the family who requests topics be avoided should include that the nurse won't bring up such topics, but if the patient brings up any difficult topics, the nurse will be honest in his or her responses and in the conversation.

When the patient is trying to protect the family, the principles of autonomy and confidentiality are paramount. In this situation, the nurse should explore the reasons why the patient is withholding information from the family. Often, there may be a past personal history or event rooted in shame, guilt, or lack of acceptance of a lifestyle. The nurse can first provide therapeutic presence in allowing the patient to process this. Additional social work and/or spiritual care support may be necessary. If appropriate, the nurse should explain that if family is to be involved in caregiving, it is helpful for them to have a full understanding of the patient's illness and comorbid conditions. The patient ultimately has the right to allow or limit information, and the nurse must honor this.

Another challenge is family dynamics. Serious illness results in either effective coping, where the family comes together, or ineffective coping, where the family falls apart. Assessment of both the patient and family reveals consistency in perspectives of family coping. Patient support may be suboptimal if there is inconsistent structure to support the ill person, or if family members are overburdened by care. Often, there are conflicted relationships due to psychological, physical, and sexual abuse; neglect; substance abuse; and past violence. Or relationships may be strained by divorce or separation. These situations are fraught with drama and divert the focus away from the patient. The nurse must understand that he or she cannot fix these problems and focus instead on the tangible health issues at hand. In addition, these situations necessitate interdisciplinary collaboration, including assistance from social work, mental health specialists, and/or addictions specialists.

The Role of Anxiety in Communication

An important phenomenon affecting nurse–patient–family communication is anxiety. Anxiety occurs in both the patient and the nurse, affecting how communication is delivered by the nurse and how it is received by the patient. The Institute of Medicine Report, *Delivering High-Quality Cancer Care: Charting a New Course for System in Crisis,* describes the role of anxiety in receiving communication.[74] Anxiety is a necessary element in everyday life. Indeed, mild anxiety helps most people do their work by being alert to issues, identifying problems, and facilitating creative solutions. Therefore, some patients may be mildly anxious and able to process information and, in fact, be quite creative. Other patients, however, may be mildly anxious and unable to process simple, basic information. It is important for the nurse to assess the patient's anxiety level and his or her ability to process each interaction.

As health issues become more serious, in particular regarding disease progression, anxiety increases to a moderate level. A patient's ability to process information becomes selective. At that point, the patient has a heightened awareness and may be thinking of possible bad outcomes including worsening disease. In this case, the nurse supports the patient by allowing him or her to voice fears and concerns and by reiterating information that the team has provided. It may be necessary to provide this information in small, easily understandable amounts.

The highest level is severe anxiety and panic resulting in total impairment of a patient's ability to process information.[75] This severe anxiety and panic often occurs in the patient when it is revealed that there are no further curative treatment options or that that the disease has progressed or advanced, resulting in a short prognosis or a terminal diagnosis. In this situation, once the clinician gives the difficult news, the patient may go into shock or panic about the news. He or she may be unable to process any further information. Understanding the patient's anxiety level is critical here. At this point, the nurse offers acknowledgment of the difficult news the patient has heard, validating reactions and discussing emotions. Nonverbal communication includes therapeutic presence. At this point, the team should refrain from any further information-sharing until the patient has had time to process the bad news.

Core Elements of Nurse Communication

Imparting Information

A primary role of the nurse is to impart information about the illness, medications, and treatments. By the nature of their scope of practice, APRNs may also offer diagnosis, prognosis, and treatment options. The task of imparting information is complex because providing information alone is not enough. Rather, information must be provided within the context of educational level, developmental level, literacy level, numeracy level, and primary language, along with psychological state and other social determinants of care.[76] When health literacy needs are not met, patients report a lack of understanding about their disease, difficulty making decisions, fears of dying, lack of understanding about unexpected symptoms, and a reliance on less credible online resources to fill gaps in understanding.[31] Low overall literacy, health literacy, and lack of English competency negatively impact clinical interactions, self-care, and caregiver support.[77]

In palliative care, patients' and families' learning needs span the continuum of care. The ability to recognize low health literacy in patients and family members is an important part of imparting information. Barriers to health literacy include the patient's physical and emotional state, prior healthcare experiences, and fear of asking questions.[78] There are many tools that can be utilized to ensure that nurses communicate effectively and meet patients' health literacy needs.[78–80] A technique called *chunking* (provide small amounts of information) and *checking* (assess for understanding) is one recommended communication strategy to addressing health literacy needs.[78] Another strategy is the *teach-back method* which involves asking patients to share their understanding of instructions or information discussed in a teaching session. Finally, using analogies and culturally appropriate metaphors can address low health literacy barriers. Given that many palliative care discussions are based on "what may happen," it is essential for nurses to tailor their communication to the individual health literacy level of patients and families to promote understanding.[77]

Most nurses do not feel comfortable or confident using health literacy strategies. The patient's educational level and understanding of medical language affects his or her information processing. If a patient hasn't completed high school, he or she may not understand complex words. It is important to use one to two syllable words. If English is a second language, attention must be paid to medical terminology and translating terminology into simple words. In one study, only 6.7% of nurses often or very frequently addressed a patient's need for easy-to-understand sources.[81] Nurses have a desire to communicate with patients with limited English proficiency to better understand their needs, yet they struggle to connect with these patients due to time management pressures.[82] In order to better care for non–English speaking patients, nurses increase their awareness of patient needs, culture, and personal growth in terms of attitude and self-awareness and the appropriate use of medical interpreters.[73,83]

Developmentally appropriate language refers to the age of the patient and his or her ability to reason. Younger children do not have complex reasoning abilities, whereas adolescents do. Information for pediatric patients and families must meet their particular needs, with modifications to make the language simpler and more concrete. The same is true for those patients with developmental delays or cognitive deficits. The stress of being in a healthcare setting impairs a person's ability to process information. Therefore, imparting information usually means providing information incrementally, at a fifth- or sixth-grade education level, to allow patients and families to best hear and process what is being said. Most words should be of one syllable, which then makes sentences simpler and easily understood.

Case Study Continued: Imparting Information

Marita met with Ms. Leary and her daughter, Patricia. She asked them what they understood of Ms. Leary's health. Ms. Leary stated that she understood her heart was bad and she had diabetes. Patricia stated that she knew her mother had many illnesses, that her kidneys were not working and her heart was failing. Marita asked if they understood what that meant. When they said no, Marita explained what heart failure was and how it was worse with her diabetes. Both Ms. Leary and Patricia had a new understanding that these conditions would not be reversed. They were appreciative of the time Marita spent with them.

In a transactional approach to communication, both nurse and patient/family contribute to and negotiate the meaning of verbal and nonverbal messages.[84] Both parties are influenced by one another as they attach meaning to messages. Environmental, social, and personal factors influence how messages are interpreted.[6] In this approach, communication is considered a collaborative ongoing process that allows for recognition of misunderstanding and finding ways to mutually honor diversity.[6] Patient-centeredness describes shared opportunities for communicating among all involved parties.

Information-Gathering

The next role of the nurse is to gather information. The most effective tool in gathering information from patients and families is the use of *open-ended questions*. Open-ended questions promote both the opportunity and richness to listen to the patient's narrative and observe nonverbal communication. The nurse benefits from the expression of values, priorities of care, coping, life priorities, and spiritual concerns. *Closed-ended questions* include "yes-or-no" questions or limited response questions and leading questions. The use of closed-ended questions, which usually focus on physical symptoms or history questions, limits the patient's response, thereby inhibiting elaboration, explanations, and clarifications of various topics.[28] Within the time constraints of clinical care, a nurse may not have enough time for a long conversation. However, a few key questions set a tone of a caring relationship. Box 5.2 offers a list of potential questions to use to start conversations.

Box 5.2 Useful Open-Ended Questions to Initiate Discussions

How are things going for you?
How are you coping with your illness?
What concerns you about your illness?
What concerns do you have about your illness?
How is treatment going for you?
What concerns you about your treatment?
What worries do you have about your illness or treatment?
What are your hopes in terms of your illness and treatment?
Who are the important people to you?
What relationships are the most important to you?
Who are the people who provide you support?
What gives you meaning in your life?
What gives you joy in your life?
What provides you with the strength to live or cope with each day?
Is there any important or unfinished business you need to attend to?

Source: Adapted from References 1, 18.

Often, important questions are asked but, as the patient starts to answer, the nurse moves the conversation on. When the nurse asks an open-ended question, it is essential to listen to the answer. Otherwise, distraction, unresponsiveness, or lack of acknowledgment is invalidating to the patient and/or family. Resentment may also result if the patient has shared something intimate without receiving acknowledgment of its significance.

Case Study Continued: Gathering Information

Marita inquired about Ms. Leary's QOL. Ms. Leary stated that it was poor as her functional status and mobility were poor, which affected her depression. Marita asked if it would be helpful to gather the family together to discuss a discharge plan with more supports to avoid rehospitalization. Ms. Leary said "yes," as she wanted to know her options. It was determined that her son Peter lived nearby and should be involved, as well as her ex-husband, if they could find him. With her permission, Marita arranged for a family meeting with the palliative team and Ms. Leary, Patricia, and Peter. They reviewed Ms. Leary's goals of care and her QOL. They asked about the changes in her health over the past few years. It was determined that, in the last year, she had declined the most. The palliative team asked about her priorities in life and her values. She said she wanted to be independent, but if this was not possible, she wanted no further treatment. Her family struggled with this. The palliative care team discussed the options and said they would talk later. Marita reviewed the discussion with Ms. Leary and her family after the meeting. They felt relief in being offered choices about her care.

Interdisciplinary collaboration is the backbone of palliative nursing, as holistic care plans can only emerge from working with other team members. Collaboration consists of interdependence and flexibility, wherein team members must work together to accomplish goals. In this case, the team elicits Ms. Leary's goals and priorities. It is important that family members receive the same message from team members. Collaboration promotes patient- and family-focused care.

Listening

Listening is an active process that requires concentrated presence and attention. Focused listening allows understanding of the patient's journey within the disease trajectory and of how the patient is processing information. During the listening process, the nurse focuses on the patient's story attentively, without interrupting, noting his or her specific word choices and concerns. One helpful technique is to begin the discussion by asking an open-ended question such as "What brought you to the hospital?" or "Tell me about what has been going on?" Specifically, the nurse observes both the spoken verbal content in the patient's responses, focusing on both what is said and what is left unsaid. In addition, the nurse notes speech patterns, tone, rapidity, and coherency. Concurrently, the nurse observes nonverbal expressions including emotion and accompanying physical movement. All of these observations will determine distress in the physical, psychological, spiritual, and emotional dimensions of care as well as which areas are a priority to address.

The nurse's use of silence is paramount. It allows the nurse to be fully present in the moment rather than mentally preparing answers or replies. Correspondingly, the nurse uses reflection to convey empathy. The nurse clarifies what has been heard by such comments as "Hmm" or "Tell me more." By acknowledging the patient's responses and exploring his or her meaning in a compassionate and supportive way, the nurse encourages the patient to explain difficult issues and concerns.[57] There may be times when the patient is silent. In this circumstance, it is appropriate for the nurse to just sit quietly, letting the patient reflect on the moment and the current situation. It is after these moments of silence that a patient may reveal sensitive information, concerns, thoughts, or past history (trauma, abuse, or illicit behaviors). The patient's revelation of information may be at a deeper level because he or she has been given the opportunity and permission to reveal such information.

There are several strategy models for palliative nursing communication.[10] One model of listening and attending is Ask-Tell-Ask. In this model, the nurse asks a question. The patient then responds with both statements and questions. The nurse then responds to the content of the discussion. The nurse closes by asking a final question to determine patient understanding.[10] A second model is the SPIKES model. In this model, *S* represents listening skills, *P* represents patient perception of the current situation, *I* represents an invitation to provide information, *K* represents offering knowledge or the facts, *E* represents emotional exploration and empathy, and *S* represents summary.[11] Another model is SOLER, where the nurse sits *S*quarely opposite the patient, with an *O*pen body posture, *L*eaning in to demonstrate empathy, using *E*ye contact as appropriate and with *R*elaxed positioning.[11] Finally, there is the NURSE model, where the nurse *N*ames the emotions, *U*nderstands the patients, offers *R*espect to the patient, provides *S*upport, and *E*xplores the patient's concerns through the use of I statements.[11] Any of these strategies is effective, and each depends on the communication style of the nurse.

Eliciting Sensitive Aspects of Care: Culture, Religion, Ethics

Sensitivity, another term for *cultural competence*, includes issues pertaining to religious, spiritual, cultural, ethnic, racial, gender, and language issues. Communication norms differ among various cultures, resulting in diverse cultural communication customs. These may include deference to healthcare providers, preference for the gender of care providers, or the appropriateness of discussion surrounding certain topics. Attending to culture is a very important aspect of communication, necessitating an appreciation of verbal cues and the interpretation of nonverbal cues. In many situations, beneficence takes precedence over autonomy. Disclosure and nondisclosure must be viewed within the context of the patient and the family, with understanding of and respect for their values and beliefs.

In order to be culturally sensitive, a nurse must be "self-aware of his or her own culture, cultural biases, and assumptions. Palliative care staff members cultivate cultural self-awareness and recognize how their own cultural values, beliefs, biases, and practices inform their perceptions of patients, families, and colleagues." [40] Understanding one's own background serves as a starting point for the nurse. This includes reflection and examination of one's ethical values and beliefs by reflecting on ethnicity and its effect on health, illness, and death; religion and its role in death, dying, and afterlife beliefs; and individual communication patterns.

Eliciting health information and understanding of illness is essential to care. In some cultures there are social norms about whether or not the patient should know health information, especially if the patient is seriously ill. Therefore, it is critical for the nurse to assess the patient's and family's religion and culture and how it affects healthcare. This includes how much, if any, information a patient wants to know. It also includes what and how much information is conveyed as dictated by culture and ethnicity. A patient may state that she wants direct communication, or she may defer to family members who would then inform her. Next, the nurse asks the patient to identify others whom she wishes to be told about her medical issues and whom she wants to make healthcare and treatment decisions on her behalf. Finally, it is important for the healthcare team to understand any religious or cultural practices that will affect health decisions.[71] Some religions do not allow surgical removal of organs or blood transfusions; others may not allow pain medications. Box 5.3 offers questions to promote the discussion of cultural and religious concerns.

If English is not the first language of the patient and family, it is obligatory to use a professional interpreter, as delineated in the National Consensus Project for Quality Palliative Care (NCP) *Clinical Practice Guidelines* Domain 5, Cultural Aspects of Care (see also Chapter 2).[40] Some hospitals offer interpreter services; some offer telephonic interpretation. Interpreters are invaluable to assist the nurse in phrasing questions and comments to be culturally sensitive and appropriate. Too often, family members are asked to interpret from English to another language, placing the family member in a double bind. Although they may be acting as translators, culturally, they must also act within their family roles. This is even more troublesome if children are translating for parents. Consequently, family translators may need to protect the patient from information, withhold information, or leave out pertinent facts. In these cases, it may be very unclear what the patient has actually been told.[85]

Box 5.3 Useful Cultural Assessment Questions

Where were you born?

Where were you raised?

How does this affect you about health and illness?

Are there any cultural considerations important to your care?

Are there other beliefs that are important to your healthcare?

Are you spiritual or religious?

How should spirituality or religion be addressed in your healthcare?

Are there any important rituals that are important to your healthcare?

How do you describe your medical condition/illness?

What do you know about your medical condition/illness?

What do you want to know about your medical condition/illness?

What do you fear most about your condition and its treatment?

How have you treated your medical condition/illness?

Who else, if anyone, do you want to know about your medical condition/illness?

Who else, if anyone, should we talk to about your medical condition/illness, treatment options, and the disease process?

Who is responsible for making healthcare decisions for you?

Are there other important people in your community involved in your healthcare?

Are there other people in your community whom we should include in your healthcare?

Source: References 1, 40.

Case Study Continued: Eliciting Sensitive Aspects of Care: Culture, Religion, and Ethics

Marita worked with the team on a discharge plan. She asked Ms. Leary about her frequent symptoms at home. Ms. Leary admitted to shortness of breath and chest pain. She stated that she didn't want strong medications due to fear of addiction. She was also afraid she would lose her independence; if she took the medications, she would need to be placed in a nursing home as the medications would make her dopey. Marita asked about her history with medications. Ms. Leary became teary and stated she was brought up to be stoic about pain. She felt like her Catholic faith dictated she should suffer for her sins. She felt guilty about her relationship with her ex-husband who had a substance use disorder from whom she contracted hepatitis C. She stated it was a bad time with him as he was abusive. A couple of times, she injected heroin, but realized this would not help her relationship. This was an unresolved issue because her children did not know about this or the whole story about her ex-husband.

Marita has been offered many openings through which to explore Ms. Leary's faith, her coping style, and her fears. Gently exploring these areas will foster trust and offer potential comfort in allowing Ms. Leary to unburden herself.

Communication Approaches

The context of communication influences the process and outcomes of interactions. Because of the rapidly changing complexity of healthcare, different methods of communication may be utilized. Of course, timing is always the first consideration and may dictate the communication method. Quill and colleagues defined "urgent" situations that necessitate immediate communication.[86] These include (1) the patient is facing imminent death; (2) the patient is talking about wanting to die; (3) the patient or family is inquiring about hospice; (4) the patient has recently been hospitalized for severe, progressive illness; and (5) the patient is experiencing severe suffering and a short prognosis. Less urgent situations include (1) the discussion of prognosis, particularly if life expectancy is thought to be between 6 and 12 months; (2) the discussion of potential treatment options with low probability of success; and (3) the discussion of hopes and fears. More "routine" palliative communication includes circumstances when stability or recovery is predicted.[86]

In-person or face-to-face meetings are most preferred as everyone is in the same room, hearing the same information, and it is easier to "read" nonverbal and verbal cues. However, with the changing work environment and scattered families, this may not be possible. Therefore, telephone, video technology, protected website, and e-mail communications all provide both benefits and downsides for the patient and family and the healthcare team.

Using technology, inclusive meetings can occur in novel ways and can cross geographic barriers. The most basic form is teleconference. A phone can be put on speaker mode to allow the family to listen to and join the conversation. Missing here is nonverbal communication, for both participants in the conference room or the family member on the other end of the telephone line. Moreover, it is important to remember that participants in the conference room need to attend to the absent family member who is listening on the phone. First, this requires removing extraneous background noises by closing doors to avoid overhead pages or shutting windows to avoid street noise because these impact the ability to hear conversations. Second, the attendees need to avoid side conversations; attend to extraneous noises such as heavy breathing near the microphone, and reduce the noise of clicking pens, shuffling feet, or the like. Third, there should be frequent check-ins to assure that listeners are hearing the conversation and understand what is being said because telephone lines can be inconsistent or there can be a time delay. Finally, all participants need to identify themselves before they speak, so the listener can follow who is saying what. At the end of the call, the summary is especially important to ensure that everyone heard the same plan.

Other more novel meetings can occur via video conferencing on mobile phones, tablets, or computer using Facetime, Google Chat, Skype, or Zoom. Of course, organizational guidelines must be followed in terms of privacy and confidentiality. This allows for full involvement by all participants because both verbal and nonverbal communication are accessible. Introductions are important to allow each participant to be viewed by the person on the computer, tablet, or cell phone. All participants must be patient with the process because of time delays occurring between when something is said on one end of the computer to when it is received on the other end. The meeting's pace may need to be slowed to accommodate this. Again, like telephones, sometimes there are bad connections that make for static or other disruption. Thus, various parts of the conversation may need to be repeated. Similar to telephone conversations, efforts to reduce background noise should be made. Overall, families appreciate the effort taken to include them in discussions, and healthcare providers are happy to have family hear consistent conversations.

E-mail and Web Technology

Many patients request the use of e-mail or social media communication, thus creating both opportunities and challenges. Opportunities include the ability for a rapid response and time-saving in gathering family and decision-makers quickly. Challenges include assuring that these modalities meet state and federal compliance with confidentiality regulations. It is vital that written communication be tailored to the health literacy level of the patient and that medical terminology be explained within the text.[87] Health literacy level can also be reflective of the patient's/family's linguistic abilities, engagement, and state of their own health.[87] E-mail communication between patient/family and nurse primarily concern the patient's physical needs or address unmet communication needs following a clinical encounter. Written responses require a balance of evidence-informed content with understanding and compassion.[88]

It is important to set guidelines for the use of these methods of communication. These methods, if done incorrectly, can compromise confidentiality. Any health information should be discussed through appropriate organizational guidelines and policies, which usually require the use of institutional secure web portals and secure correspondence. Nonetheless, only routine communication should occur this way. Expectations should be set for appropriate overall use of e-mail or phone contact. Moreover, there should be one person designated to communicate with the team in addition to the patient, thereby discouraging multiple e-mails by different family members to the healthcare provider. Patients and families should be given guidelines about not using this method when the clinician is off-service or on vacation.

The clinician should delineate the types of communication that are appropriate for e-mail or Web-based requests. It is important that patients understand that clinical assessment is difficult to accomplish via e-mail. Clear explanation should cover the principle that e-mail does not substitute for in-person visits and that complex e-mails usually necessitate a face-to-face visit. Usual e-mail or Web-based correspondence includes nonurgent medication requests or refills, durable medical equipment requests, home service requests, follow-up of a stable response to a new treatment, referral information, and scheduling of follow-up appointments or routine check-ins.

The response time for such communication should be considered. Patients need to be informed of expectations in response times. Because clinicians cannot monitor these sites during their clinical duty hours, there may be a lag of several hours in response time. All health facilities have protocols for urgent and emergent issues to be attended to, and any patient emergencies or urgent issues should be directed to 911 or the office triage service. All clinical assessments should occur by phone and go through the triage system.

Patient and Family Meetings

Patient and family meetings are a wonderful but underutilized tool. These meetings promote respectful and sensitive delivery of information in a timely, thorough, current, comprehensive, and accurate fashion. The patient may or may not attend depending on his or her condition, decision-making capacity, and preference for involvement. It can be helpful to hear consistent messages. For the family, it is a time to meet the various team members and understand their roles. Family meetings help the family understand the disease process and options of care while providing reassurance that a plan is in place and that everyone is working toward a consistent goal.[89,90] The family meeting also provides clinicians an opportunity to collaboratively formulate a plan of care that is consistent with the goals and wishes of the patient and family.

There are several types of meetings that occur within the context of palliative care: information meetings, ACP meetings, bad news discussions, and code status discussions.[90] The first meeting type is a straightforward information meeting. These meetings help form a working relationship between the patient and family and the care team. There may be no particular agenda other than to convey information about the patient's current status or the nature of the illness and its symptoms. There may be no decisions to be made and no future planning. Other topics include predictions about the course of illness and treatment options. There may be a discussion of home care, symptom management, medications, and nursing support.

No matter the reason for a family meeting, there are guidelines for holding a meeting. Before calling a family meeting, it is important to maximize the effective use of time by clarifying the meetings' goal. A pre-meeting should be held to clarify the messages to be conveyed and determine who should lead the meeting; the leader may not necessarily be the physician.[90] The nurse may facilitate the initial conversation by serving as a focal point for continuity of care. Organizational culture may dictate who may lead family meetings. For more complex or contentious families, having a team meeting specifically to plan strategies to deal with a difficult family is time well spent. Consideration should be given to the attendance of essential healthcare providers.

The actual steps for a family meeting are fairly straightforward and based on common sense. There are eight steps: (1) finding an appropriately private space for the meeting; (2) introducing all the participants at the meeting; (3) using open-ended questions to establish what the patient (and family) knows; (4) determining how the patient wishes the information to be presented; (5) presenting information in a straightforward manner, using understandable language, in small quantities, and with pauses for processing and questions to assess understanding; (6) responding to emotions; (7) clarifying goals of care and treatment priorities; and (8) establishing a plan.[91] Box 5.4 reviews the process of a family meeting for sharing information, delivering bad news, or clarifying life-sustaining treatments.

Because of their perceived formality, scheduled meetings tend to take on more importance than informal meetings. Several steps are important to their success. After introductions have been done, the goals of the meeting can be stated. Then, using open-ended questions, the patient can be asked about his or her understanding of the medical condition and situation. This is followed by ascertaining the patient's worries and fears, how much information the patient wants to know, and which other people the patient wants to be informed concerning clinical issues or involved in his or her care.[92] This includes determining patient and family understanding of the illness and their values, preferences, and beliefs, along with their informational needs for the decision-making patient who is hesitant to express emotional concerns and who may need prompting or an invitation to speak. The designated

Box 5.4 The Family Meeting

Pre-meeting planning

1. Conduct clinician pre-meeting to assure consistency of message and process.
2. Clarify goals of meeting with patient and family as well as staff.
3. Decide on the essential people to attend the meeting—patient, family, and healthcare providers.

The family meeting encounter

4. Arrange appropriate setting.
5. Introduce all participants in room and his or her relationship to patient's care.
6. Review goal of meeting.
7. Elicit patient/family understanding of care to date.
8. Review current medical condition.
9. Attend to questions.
10. Review options for care.
11. Elicit response from patient if decisional.
12. Elicit response from family in terms of what patient would choose for himself or herself, if he or she could.

Summary

13. Review plan. If agreement—then decision. If no agreement—what follow-up is planned?
14. Document meeting—who attended, what was discussed, and plan.

Source: References 1, 92.

meeting leader offers a summary of the planned care. The next part of the meeting addresses questions and issues that require clarification. After this discussion, the leader summarizes the issues and develops a plan of care in collaboration with the patient and family. One of the most important yet often neglected tasks after the meeting is documentation.[90] The names and titles of the people who attended, the issues discussed, and the decisions made should be recorded in the medical record.

Scheduled Meetings and the Role of the Nurse

Scheduled meeting times are critical in allowing the patient to prepare emotionally and psychologically for any potential news. This includes allowing for the presence of the patient's support network to hear and validate information conveyed. Nurses play a vital role in these meetings because they are often responsible for organizing the meeting. Before the meeting, the nurse may assess the patient's physical, emotional, and psychological concerns to be conveyed in a meeting. This information can assist the team in planning discussion points at the scheduled meeting. After the meeting, the nurse can follow-up and reinforce information communicated.

Nursing presence at any discussions—particularly when important information is conveyed—cannot be overemphasized. The team may need education regarding nursing's pivotal role in patient advocacy, particularly in supporting the patient after difficult conversations.[93] If a primary nurse is not able to participate in important discussions, a nursing colleague may participate to offer a nursing perspective. If this is not possible, it is essential that the team review the specifics about the conversation with the nurse—in particular, the news delivered, the phrasing used, and the patient's response. This allows the nurse to provide collaborative follow-up support. Sometimes the nurse may be reticent and wait to be invited rather than being proactive in participating and facilitating discussions. This reticence can cause the nurse to feel uninformed and undervalued, ultimately leading to ineffective care.

The nurse may facilitate the initial conversation by serving as a reference point for the patient and family in conveying important concerns or worries gleaned from previous interactions. Often this occurs at the beginning of the meeting and personalizes the discussions to the specific needs of the patient and family. In addition, the nurse may act as a translator between the medical team and the patient, facilitating information-sharing, interpreting information and medical jargon in language the patient understands, and also ensuring that the members of the care team understand the patient's words and language. If the patient/family agrees to the plan, the meeting can end with a synopsis of the meeting and the decisions made. If the family disagrees, another meeting can be suggested. Box 5.5 offers questions to promote conversation about coping. Difficult or overbearing families may shift the conversation to their own needs and concerns. If overbearing or difficult patients or families obstruct meetings with anger, blame, and criticism, it is important to reinforce the goals of the meeting and to restate that the focus of care is on the patient.[94] It may be necessary to set ground rules about appropriate behavior. After the completion of such a meeting, these family members may be offered resources and referrals to help with their own individual grief and coping.

Box 5.5 Questions to Address Patients' and Families' Coping

How have you/your family coped with crises or difficult situations in the past?

Have you/your family been through something like this before?

How did you/your family react/cope?

Can you identify/anticipate any potential areas of concern for you and your family?

Have you told your family what you would want in terms of life-prolonging treatments?

Did the patient ever tell you what they wanted for themselves in terms of life-prolonging treatments?

Is there anyone you need to see? Is there anyone you think the patient would like to see?

Who is supporting you now? Is there anyone you'd like us to call?

Who could you call if things became more serious, difficult, or you needed emotional support?

Source: Revised from Reference 21.

Advance Care Planning

ACP is essential to palliative care; it serves as a valuable guide to inform the healthcare team about the patient's care goals. The NCP's *Clinical Practice Guidelines for Quality Palliative Care* (3rd edition) describes how "person-centered goals, preference, and choices form the basis for the plan of care."[40] ACP is a social process based on the ethical principle of autonomy of the patient. ACP is a process that promotes patient control of his or her health. It prepares for lack of capacity in decision-making and relieves the burden of decision-making on others. These comprehensive discussions promote the determination of the patient's values, goals, fears, and concerns while also developing the core topics for patient education, including the right to high-quality pain control and symptom management.

There are three discrete elements of ACP: designation of a healthcare durable power of attorney, completion of an advance directive, and out-of-hospital resuscitation orders. A *healthcare durable power of attorney* defines the person whom the patient designates to make decisions if or when he or she is unable to do so.[63] This is otherwise known as the *surrogate decision-maker*. It is beneficial for the nurse to help describe this role as well as to educate both the patient and the surrogate decision-maker on the role and when it is invoked.[2] Moreover, the nurse can facilitate discussion between the patient and the surrogate decision-maker about the patient's wishes.[2] The designation of a healthcare durable power of attorney can take place on its own or within an advance directive document such as a living will. There are several popular and easily accessible documents available for free, for example *Five Wishes for Adults* or *My Wishes for Teenagers* from Aging with Dignity and *Advance Health Care Directive Fact Sheet* from the Coalition for Compassionate Care of California and *Honoring Choices*.[95–97]

Because the process of ACP involves setting goals of therapy, developing care directives, and making decisions about specific forms of medical therapy, it is more effective if anchored in personal experience. For instance, if a patient has had a family member or friend with chronic illness, poor health, and/or a terminal illness, they may be able to reflect on the actual aspects of care. For chronically ill, debilitated, and terminally ill patients, planning topics include decisions about life-sustaining therapies (code status), medically administered feeding and hydration, and palliative and hospice care. Box 5.6 offers questions to initiate ACP conversations.

It is essential that culture, health literacy, and linguistic literacy are considered within the process of ACP.[40] Discussions need to consider and respect the education level of the patient in order for the patient to make meaningful choices. The use of interpreters is paramount to reflect the nuances of culture and language differences. In some cultures, any conversation related to death, dying, or planning at end of life is inappropriate discussion. In other cultures, the use of death and dying terminology may not be used, and euphemisms may be used instead (e.g., "passing on"). Additionally, discussions about limiting the use of life-sustaining technology may be seen as akin to hastening death. These viewpoints must be respected and supported, even if the healthcare team disagrees with them.

Ideally, ACP and completion of advance directives should begin within preventive or primary care settings. These discussions are best completed over time, which normalizes them. This allows opportunity for reflection and discussion with family and friends about possible scenarios, which in itself may prepare the patient for the course of disease. However, if not initiated early, then

Box 5.6 Initiating Advance Directive Conversations

Normalizing comments/questions:

I'd like to discuss a topic I bring up with all my patients.
I wonder if you have ever imagined being really sick and what treatments you would and would not want.
I'd like to talk with you about possible health decisions in the future, if you became really ill.
I often like to make sure I understand my patients' preferences and wishes for aggressive care if there were a serious change in condition.
I would like to discuss your feelings about going to the emergency room, the intensive care unit, and being on life support.
In order to best support you, I wonder how you define quality of life and what is important to you?

Inquiries of patient's understanding of illness:

What do you know/understand about your current health situation?
What do you know/understand from what the doctors have told you?
What more do you want to know/understand about the current situation?

Inquiries to elicit hopes and expectations:

What do you hope for in the future?
What do you expect from your condition in the future?
Have you ever thought about if things don't go the way you hope?
How can we help you live in the best way possible for you?
How do you wish to spend whatever time you have left?
What activities or experiences are most important for you to do to maximize the quality of your life?

Inquiries to elicit thoughts regarding cardiopulmonary resuscitation:

Have you ever thought about life support or life-prolonging treatment measures?
If you should stop breathing or your heart stops beating, would you want us to use "heroic measures" to bring you back?
Have you ever thought about if anything were to happen to you and you could not breathe on your own or your heart could not work on its own, what would you want?
Have you given any thought to what kinds of treatment you would want or not want if you become unable to speak for yourself in the future?

For the family:

Did your loved one (name of person) ever tell you what he or she wanted for himself or herself?
Did he or she (name of person) ever talk about life-prolonging therapies?
Did he or she (name of person) witness other family members or friends undergoing treatment and comment on his or her own preferences for care?
Did he or she (name of person) ever talk about the care of another family member and state whether he or she would have wanted the same type of treatment?

Source: Revised from Reference 1.

discussions should occur before acute, disabling events and, hopefully, before the end stage of a terminal illness. Otherwise, they are laden with greater emotional burden. Unfortunately, there are a number of reasons that these conversations do not occur, including reluctance to initiate such discussions due to time constraints, lack of comfort with such discussions, lack of skills in such communications, and fear of upsetting the patient even though she or he may wish to have the conversation.[2]

There seems to be agreement on the importance of (1) naming a surrogate decision-maker, (2) documenting care preferences, (3) promoting illness understanding through education, (4) exhibiting a willingness to discuss death and dying, and (5) completing personal finances and business affairs. Patients differ in the extent to which they wish to participate in treatment decisions; therefore, it is essential to determine this. Being provided with adequate information and direction in realistic healthcare choices is critical. Without any structure or context, the weight of these decisions can cause patients and families to feel a sense of self-blame or loss of confidence in the team. This is because the burden of stopping care is heavy, and patients and family may feel that this is the same as "giving up."

To promote consistency of care preferences in the community, out-of-hospital or community resuscitation medical order sets are appropriate. These orders usually consist of do-not-resuscitate orders because the default in our health system is full resuscitation. However, they may be known as Comfort Care Orders, Allow Natural Death Orders, Physician/Provider Orders for Life Sustaining Treatment (POLST), or Medical Orders for Life Sustaining Treatment (MOLST). As stated on the POLST website, "The POLST Form is a set of medical orders, similar to the do-not-resuscitate (allow natural death) order. POLST is not an advance directive and does not substitute for naming a health care agent or durable power of attorney for health care."[98]

Survival estimates affect patient decision-making, thereby necessitating accurate prognostic information. However, there are several barriers to this. First, physicians are poor at estimating and reporting accurate survival times to patients.[99] Second, patients often receive conflicting information from various team members. Unsubstantiated information on the Internet adds furthers disparity to prognosis. Patients appear to want honesty, along with optimism and hope.[99] Nurses can promote the consistency of such information by being present when such information is delivered. Given their knowledge and working relationships with professional colleagues, nurses may also temper overly optimistic survival times.

A change in focus from future cure-oriented treatments to current functional status can facilitate realistic, authentic conversations. For instance, if the patient is talking about more treatment, but he or she is essentially bed-bound, the opportunity is presented to discuss the reality of actually participating in such treatment. Having the patient consider potential situations may be helpful. One such statement may be, "There may come a time when you need help breathing with a ventilator. But we may not be able to get you off the machine. What should we do then?" Such a scenario may offer understanding of the seriousness of the illness, realistic options for therapy, and potential circumstances of death. The result is that the patient may share his or her values and express preferences for care. The result may be a sense of control, a sense of trust with healthcare providers, and a sense of resolution in certain aspects of one's life.

Advance Care Planning and the Role of the Nurse

A central communicative role of the palliative nurse is to identify opportunities to engage patients and families about ACP. Discussions of ACP are identified as essential task-focused communication to be accomplished during the first visit or to be shared during interdisciplinary team meetings when reviewing patient plans of care.[100] The goal of ACP discussions is to impart information to help the patient and family understand the entire situation of the patient's illness; this requires the use of clear explanations, a review of options, and a formal clarification of the difference between hospice and palliative care.[2,31] Common barriers to discussions about ACP include patient or family unwillingness to listen, noncommunicative patients, nurse discomfort, and perceived physician hesitance to discuss the topic.[31] Importantly, discussions about ACP need to be reviewed during interdisciplinary team meetings to ensure that all team members are aware of the patient's preferences.[101] Nurses are encouraged to engage in relationally focused communication as part of these discussions and address psychosocial and spiritual concerns.[2,102] Nurses may often serve as a translator as well. Although families and patients have questions about their healthcare, many of them may not understand or be familiar with the medical terms often used by nurses and other clinicians.

Ongoing Discussions of Goals of Care

The patient's priorities and needs shift, resulting in a changing and evolving care plan. Many palliative care specialists have emphasized the importance of systematic meetings to discuss the patient's concerns. In particular, the early introduction of such conversations in the disease process promotes better outcomes.[61,91] These outcomes include more informed choices, better palliation of symptoms, and more opportunity for resolution of important issues.

Nurses may be particularly helpful in advocating for patients when they are unable to speak for themselves. In these cases, the nurse may assist the surrogate decision-maker to convey the patient's wishes by inquiring more about the patient's personal history. Asking the patient such questions as "Are there things that would be left undone if you were to die sooner rather than later?" that stimulate thought and discussion about dying and important life closure issues, such as healing broken relationships and completing financial transactions. However, a nurse may ask this in a different way, such as, "Are there things you need to do in case things do not go as well as we hope?" Encouraging patients to hope for the best outcome while preparing for the possibility that treatment may not work—"hope for the best, prepare for the worst"—is helpful in guiding the patient.[103] Again, the advocacy role facilitates the provision of all essential information the patient needs to make choices. This includes managing care at home and support structures for family caregivers. Box 5.7 offers questions for ongoing care.

As patients decline, they may wish to defer to family or surrogates. If the surrogate decision-maker is unsure about the patient's wishes or if no advance directive is available, the nurse can pose questions to prompt clarification on the values and preferences of a patient. These include, "What type of person was the patient?," "What did he or she value?," "Did she or he ever comment on another person's health situation in terms of what they would want or not want?," and "What stories or memories can you recall from his or her life that illustrate his or her values?" In addition to helping to clarify

Box 5.7 Questions for Discussion About Ongoing Care

How do you spend your days?

What is an average day like for you?

If you were not ill, how would you like to spend your time?

How has your condition/disease interfered with your daily activities?

What practical problems/issues have occurred as a result of your illness?

Which symptoms bother you the most?

How are things with family and friends?

Have you been feeling worried, sad, or frightened about your illness?

Do you have a preference for where you spend your time, at home, in the hospital, or at health appointments?

Source: Revised from Reference 21.

a patient's wishes, addressing these questions may also serve as a healing review of the person's life and help identify what has brought them meaning.

Case Study Continued: Care Planning

With Marita's assistance, Ms. Leary was discharged home with a palliative care team to enable her to stay at home. Chaplaincy spent time with her discussing her faith and her need for forgiveness. Social work met with her to allow her to consider her legacy and whether she wanted to tell her children her long-kept secret. Ms. Leary was admitted several times for symptoms and appreciated the continuity of care in having Marita as her nurse. When she was at the end of her life, she moved to a hospice facility.

Bad News Discussions

In palliative care, bad news includes a poor disease diagnosis, recurrence, disease progression, lack of further curative treatments, lack of any treatments to stabilize disease, transition to comfort care, and a terminal prognosis. Bad or unfavorable medical news may be defined as "any news that drastically and negatively alters the patient's view of her or his future."[18]

Nurses often convey a variety of bad news to patients and families such as cancellations or delays in treatments, confirmation of a serious or life-threatening illness, decrease in QOL, and care-setting options.[104] Nurses working in inpatient care settings, especially critical care nurses, are particularly prone to bad news disclosures, as they develop relationships with patients and families in a constantly changing environment.[105] Deciding who delivers the bad news may depend on multiple factors: the relationship of the patient with the team, the clinician the patient most trusts, and, sometimes, institutional culture or practice guidelines.

Bad news disclosures are emotionally charged events for both patient and family and for the nurse and require continuous assessment of patient understanding, fears, and information preferences.[104,105] Coyle and Sculco beautifully describe the emotional setting of giving bad news for the clinician and the patient[106]:

> Is it possible for any news, transmitted by a doctor [or nurse] to a patient, to be "good news" in the face of advancing disease that is not responsive to chemotherapy? The doctor [or nurse] is in a position of having to give information that the patient does not want to hear, and yet the patient needs to have the information in order to make necessary life decisions. Does it matter how the information is given when medical information itself can remove hope for continued existence? In a way, both parties—the doctor and the patient—are engaged in a communication dance of vulnerability. The physician is vulnerable because he/she must deliver the facts, whatever they may be, and the patient is vulnerable because he/she doesn't want to hear any more bad news.[106]

Physicians and nurses are part of this communication dance. Patients with advanced disease generally want to have this information. Paradoxically, however, although patients may want information, clinicians may be reluctant to initiate such a discussion.[107] Physicians may avoid telling the patient too much because they want to avoid feelings of failure. While the principle of delivering bad news in the context of the patient's and family's understanding is essential, a large underlying factor is the relationship of the caregiver with the patient and family and their understanding of the condition and its trajectory. Nurses, particularly APRNs, along with their physician colleagues, communicate a wide range of bad news to patients. However, registered nurses may feel uncomfortable in meaningful conversations because they may perceive lack of permission, authority, or scope of practice within their organization. They may also lack communication skills, communication education, or role modeling in effective communication.

Behaviors for effective presentation of bad news may be grouped into four domains: (1) preparation, (2) message or content delivery, (3) responding to the patient (and family), and (4) closing the encounter.[103,108] Essential within the preparation of giving bad news is attention to the healthcare provider's own emotional stress. There may be a range of possible feelings: guilt, lack of control, failure, loss, fear, or resentment.[85] Awareness of these feelings allows for clarity in ownership of issues and a more objective encounter. Nurses, in particular, may also need to deal with their own emotions either from a long-term relationship with the patient or family or from a connection in which there was a personality match.[104]

Devastating news can come in many forms for patients and families, and nurses cannot expect to anticipate with accuracy what news will be considered bad. When information is bad, as interpreted by patient and family, a nurse's compassionate presence does not mean having the right answers or all the answers, but rather just "being there" for patients. Mindful presence in bad news disclosures can attend to the spiritual, religious, and existential aspects of care. Nurses are often charged with regularly exploring and assessing patient fears, beliefs, preferences, and desires. Simply providing therapeutic presence and talking about these concerns is noted as very meaningful to patients and families.[109]

Recommended steps for family meetings about bad news focus on the following: (1) ensuring privacy and adequate time, (2) assessing patients' understanding, (3) providing information about diagnosis and prognosis simply and honestly, (4) avoiding the use of euphemisms, (5) encouraging expression of feelings, (6) being empathetic, (7) giving a broad but realistic time frame regarding

Box 5.8 Delivering Bad News

1. Prepare for the meeting:

   Determine with the patient whom they want present.

   Determine with the team which health care providers should be present.
2. Create a comfortable, quiet setting with seating for all participants and free of interruptions. Obtain interpreter as needed.
3. Clarify and clearly state your and the patient's goals for the meeting.
4. Determine what the patient and family know about the patient's condition and what they have been told.
5. Provide the foundation of a brief overview of the patient's course and condition for understanding of the entire group.
6. Give a warning of the news to come:

   "Unfortunately, I have some bad/difficult news to share with you." "I wish I had better news." "This isn't the information I expected."
7. Pause.
8. Give the bad news.
9. Sit quietly and allow the patient and family to absorb the information.
10. Wait for the patient to respond.
11. After being silent, check in with the patient such as by saying, "I have just told you some difficult news. Do you feel comfortable sharing your thoughts about this?" This may help the patient verbalize concerns.[18]
12. Listen carefully and acknowledge the patient's and family's emotions, such as by reflecting on both the meaning and the effect of their responses. Give an opportunity for questions and comments.
13. Provide a summary and give description of follow-up.

Source: Revised from Reference 1.

prognosis, and (8) arranging review or follow-up.[91] Other points are summarized in Box 5.8.

Often, in response to bad news, patients may ask difficult questions such as, "Why me?" Rather than feeling the need to answer, the nurse might offer therapeutic presence. Acknowledgments, such as "That is a tough question," allows the nurse to comment and explore further. This can be followed-up by, "Can you tell me what you are thinking right now?" Or, another statement could be, "That was difficult news, how was it to hear?" By acknowledging and normalizing the patient's feelings, the nurse invites the patient to voice his or her thoughts, feelings, and concerns. By sharing the patient's distress, the nurse may reduce the patient's sense of isolation and suffering. After listening to the patient's and family members' fears and concerns, it is essential to provide accurate, hopeful information. When the patient asks whether he or she can partake in some activity that may or may not be in a realistic time frame, the nurse can respond, "I wish that were possible, but I am worried it won't happen." Or, "I hope that you can do that, too, but if you can't, here is what we can do in the meantime." The issue of abandonment should be deliberately addressed. This can be achieved with such words as, "I wish things were different. But no matter what, I will be there to support you in your decisions and promote your quality of life." This allays fear that even though the patient can no longer tolerate treatment, providers will continue caring for them.

Prognosis

Another common and difficult question is the patient's response to such news with the question, "How long do I have to live?" Responding to and acknowledging such a question normalizes the discussion around death and dying. The nurse may choose to answer in several ways, depending on his or her comfort in these discussions. One response is, "Are you asking for a specific timeline?" Here, the nurse is trying to ascertain whether the patient is asking about dying or is thinking of a certain event that he or she wishes to live to experience. Another response is, "How long do you think you have to live?" This allows patients to voice concerns about time and offer their own impression of their remaining time. The patient may say, "Not long, but I wanted to see how long you thought," thus comparing input from different members of the team. A third response may be along the lines of, "Why are you asking that question now?," "What makes you ask that question now?," or "Why do you ask?" This invites the patient to share his or her fears and concerns about dying. The nurse may also reflect on difficult information with, "I imagine it is very frightening not knowing what will happen and when. Do you have particular fears and concerns?" Finally, if the anticipated survival time is short or the nurse is uncomfortable, he or she may reply, "What has the team told you?" In this case, the patient may state that the team has given a certain estimate of time, or the patient may be seeking validation of the prediction.

When it is appropriate to offer a timeline, it is helpful to give a range of time rather than exact times. Instead of the specific time of 2 weeks or 6 months, it is more helpful to say, "weeks to months." This prevents the patient or family from making a calendar and ticking off the days until death. In those cases, if the patient surpasses the exact time, there is often anger about the countdown. However, when death is imminent, it is helpful to say "hours to days." It is also useful to explain what supports that timeline, such as significant changes, signs and symptoms of dying, or rapid disease progression. This allows the patient and family to prepare for their final time together.

Discussion of Life-Sustaining Treatments

Often when patients are critically ill and have advanced disease, the healthcare team seeks clarification on the use or continuation of life-sustaining measures. Life-sustaining measures may include vasopressors to help the heart pump more efficiently and effectively, dialysis for kidney failure, antibiotics for infections, and medically administered nutrition and hydration. "Code status" is commonly defined as the use, or limitation of use, of life-sustaining therapy in the event of clinical deterioration of respiratory function and/or cardiac arrest. Major life-sustaining measures within cardiopulmonary resuscitation (CPR) include invasive ventilator support consisting of nasotracheal or endotracheal intubation, noninvasive ventilator support (CPAP, BiPAP), and defibrillation (cardiac electroshock). The use, continuation, or discontinuation of life-sustaining measures are all necessary aspects to these discussions.

Currently, when a patient in any setting experiences a cardiac arrest and/or respiratory failure, the default is full resuscitation. Thus, CPR is performed unless the patient or the patient's surrogate has indicated do not resuscitate (DNR) and/or not to be intubated and supported with mechanical ventilation—do not intubate (DNI). The public has little understanding of the reality of implementing CPR. Only 6–10% of people survive CPR outside of hospitals, while inpatient rates are around 24%.[110] These statistics decline in patients with serious life-threatening illness. Additionally, patients and families need to be informed that returning to previous function and QOL is unlikely. Rather, if the patient survives, functional status often diminishes along with QOL. To dispel concerns of abandonment, it is particularly important to reassure the patient, family, and surrogate that even though CPR will not be performed, all beneficial care will be actively provided. The team should offer recommendations because patients and families cannot make responsible decisions without survival rates, prognosis, and resultant QOL following CPR.

The process is similar to other patient and family meetings. The recommended steps include (1) establishing an appropriate setting; (2) inquiring of patient and family what they understand of the patient's condition; (3) finding out what the patient expects for the future; (4) discussing resuscitation within the context of the patient's condition; (5) eliciting the patient's understanding of present condition and thoughts of the future, including the context in which resuscitation would be considered; (6) responding to concerns and emotions; and (7) developing a plan.

There are several important concepts around code status discussions. Use of medical vernacular, such as "full code" or "no code" and "Do you want everything done?" is ambiguous at best. These terms simply indicate whether or not to perform a procedure, offering little insight into the patient's goals of care. Instead, code status that includes definition of QOL, preferences, values, or beliefs guides care decisions. Box 5.9 offers some exploratory questions on QOL.

Box 5.9 Questions to Facilitate Quality-of-Life Discussions

How is your quality of life? How would you describe quality of life?

What would not be quality of life? What would be an unacceptable life?

Is this how you thought disease-focused treatment or advanced illness would be?

What would make this time especially meaningful for you?

What makes life worth living for you?

How have your religious or spiritual beliefs been affected by your illness?

Source: Revised from Reference 1.

The focus of discussion on the use of life-sustaining technology is to review the anticipated benefits and burdens of interventions. The challenge is that patients need to understand that CPR statistics are related to people without a life-threatening illness. A possible statement could be, "With all the treatments we have done, you still have a serious illness that is incurable. Full code will mean returning to the intensive care unit. This would cause further weakness and debility and keep you away from your family." Or another statement could be, "We know that resuscitation is not without pain from chest compressions and discomfort of ventilator tubes. You have stated you did not want to be in restrained in any way." However, the process of determining the use of life-sustaining treatment is incomplete without documentation. Both the plan and the context of the conversation must be documented in the record and accessible to other healthcare professionals. Ideally, it should be accompanied by a completed state-recognized comfort care/DNR order forms.

According to the position statement *Nursing Care and Do Not Resuscitate (DNR) and Allow Natural Death (AND) Decisions,*[111] "Nurses must advocate for and play an active role in initiating discussions about DNR with patients, families, and members of the health care team." The team can offer the patient and family a plan that focuses on aggressive pain and symptom management, psychological support, and better QOL. They can then ask for agreement from the patient and family, thereby allowing the patient and family to assent to a plan. Assent means the family agrees to the plan without having to take on the burden of choosing a specific option. Consent means the family is offered a range of options, and they choose which option. By assenting, the burden of the decision is removed from the family and placed on the care team. For many families, this feels like less of a burden because the team makes the difficult decision. It may still be the same plan, but the team has allowed the patient and family to "unshoulder" the burden or weight of the decision.

Nurses are often ideally positioned to contribute to conversations about EOL care and decisions, including maintaining a focus on patients' preferences, and to establish mechanisms to respect the patient's autonomy.[112] There are often circumstances when the patient and family convey their overwhelming sense of pressure or responsibility about the decisions they are being asked to make. When this occurs, often the responsibility of making such a decision is too great for patients and families. They may feel that by making a choice to refuse resuscitation, they are "pulling the plug." In these situations, nurses can take an active role in creating an interdisciplinary care plan as described by ANA's Position Statement *Registered Nurses' Roles and Responsibilities in Providing Care and Support at the End of Life*. "Nurses are obligated to provide care that includes the promotion of comfort, relief of pain and other symptoms, and support for patients, families, and others close to the patient."

Discussions of Life-Sustaining Treatments and the Role of the Nurse

Nurses are heavily invested in clarifying code status. This arises from the wish to avoid inflicting further suffering on patients with serious and life-limiting illness. Nurses fear situations in which the primary physician is unavailable and they must deal with a covering physician unfamiliar with the patient and his or her goals of care. Therefore, most nurses want to quickly establish the code status with providers familiar with the patient's medical condition.

It is essential that nurses understand the use of life-sustaining treatments among a variety of patient populations. Explaining the benefits and risks of such treatments to patients and families requires nurses to be familiar with both the appropriate and inappropriate use of life-sustaining treatments.[113] Incorporating clinical ethics in decision-making about life-sustaining treatments is a key component in discussions with family.[114] There are several important communication points regarding life-sustaining measures. First and foremost is that the nurse remains present and open to the patient's and family's rationale about these difficult issues. Second is that discussion with the patient and/or the patient's surrogate includes (1) perception of the benefits and burdens of life-sustaining treatments and the suffering with or without these interventions; (2) any values, beliefs, and cultural issues of the patient and family that affect the decision or need for such interventions; (3) the available data regarding the benefits and burdens of the interventions; and (4) collaborative decision-making about these interventions to meet the patient's goals.

The significant role of nurses in providing information and family guidance during challenging decision-making about life-sustaining measures cannot be overemphasized. When the patient is dependent on a ventilator, the nurse must assess the patient's literacy level and understanding along with any visual or auditory impairments in order to teach family members how to communicate with the patient.[115] Teaching the patient and family how to use communication tools such as picture/letter boards and to understand nonverbal cues (e.g., head nods, mouthing words) and creating an appropriate environment (visual and proximal positioning) to facilitate patient–family communication are the responsibility of the nurse.[116]

Because of 24-hour presence with the patient, the nurse may be the one to whom the patient and family turn for explanations, recommendations, reassurance, validation, and support. Questions to the nurse may focus on the meaning of medical jargon such as "CPR/DNR/DNI," presser support, ventilators, and so forth. This is usually followed by patient and family questions such as, "What do you think?" or "What should I do?" The nurse must first define these terms and their intended effect. By educating the patient about the actual intervention and likely outcome, a nurse may be able to reassure the patient.[68] The nurse can offer the facts and reflect back the patient's values and preferences such as, "Mr. X, you told me you want to be comfortable and not return to the hospital. We can get support at home to keep you comfortable and aggressively treat any symptoms." Reassurance and support for the appropriateness of preferences and decisions develops from questions such as, "Do you feel I made the right decision?" or "What would you do?" Patients may need reassurance that the nurses will continue to provide care. The nurse may respond with, "I support your decision."

Conversations About Medically Administered Hydration and Nutrition

Numerous cultures place great social and cultural importance on drinking and eating. When patients are not able to take food or fluid by mouth, medically administered hydration and nutrition may be provided through the gastrointestinal tract using a nasogastric or gastric tube or may be administered intravenously. Finally, for some cultures, intravenous fluids and nutrition may be necessary to prevent any sense of hastening death. Many people believe that not eating and drinking causes great physical suffering. Medically administered hydration and nutrition may alleviate any guilt felt by patients and family arising out of the feeling that they had not "tried everything." Therefore, it is necessary to discuss the potential benefits and burdens of both instituting and withholding medically administered hydration and nutrition. The rationale for and against these procedures is discussed in Chapter 70, "Ethical Considerations in Palliative Care."

Conversations About the Transition to Palliative Care or Hospice

The transition in care away from curative-directed therapies is often an emotional time for patients, families, and clinicians alike. Patients may feel a sense of sadness, anger, denial, and loss of control to the disease. Families may finally come to terms with the reality of the situation or the serious nature of the illness. Physicians may feel a sense of failure for not curing the disease and frustration with the lack of any further medical options. Nurses may feel grief from the impending termination of the patient and family relationship. The focus of care shifts from curing the disease; from physical cure to emotional and psychological healing.

A direct nursing approach is helpful, stating, "We are no longer able to cure or control your disease. We would like to optimize your quality of life, manage pain and symptoms to avoid suffering, and promote optimal functioning. We have expert nurses who care for patients with life-threatening illness, helping you avoid the hospital. We will work with them to care for you at home." This allows the patient and family to understand that they will continue to be cared for and not feel abandoned. Such discussions lend themselves to completing legal and financial business. This allows for life closure in preparation for death and legacy work. Usually, this also includes attending to psycho-emotional-spiritual work. For the family, such discussions promote preparation and planning for a home death and strategies for sustainability in caregiving.

The nurse has a central role to empower the patient at this time. This is accomplished by a continued dialogue about hopes, preferences, and QOL. Each situation is individual and cannot be determined by an algorithm or recipe approach; personalizing the experience promotes emotional healing. Guidelines for initiating conversations during the last phase of life include (1) focusing on the patient's unique illness experience, (2) discussing issues of closure, (3) promoting discussions about pain and symptom management at the end of life, (4) addressing and planning for the preferred site of death and who will provide care for them, (5) facilitating home health and hospice arrangements, and (6) promoting a respectful death. Box 5.10 offers questions to open exploration of changing goals. Nurses offer information to patients and families about resources and transitions of care. This includes hospice, home health, and other community-based healthcare resources, when such resources are consistent with the patient's and family's values, beliefs, preferences, and goals of care.[3] The nurse is then responsible for the coordination and communication of the plan. He or she promotes continuity of care and continued support in the home. The hospice, palliative, or home care nurse must educate the patient and family about necessary caregiving skills concerning medications, equipment, and personal care.

Box 5.10 Questions for Changing Goals of Care

What do you understand about your disease and current condition?

What do you understand about further treatment?

What are some of the concerns you have at this time?

What, if anything, are you worried about or afraid of?

Given the severity of your illness, what is most important for you to achieve?

Have you given any thought to what kinds of treatment you would want (and not want) if you become unable to speak for yourself in the future?

We want to focus on maximal comfort and optimal functioning with as much support as possible. Is that okay?

How is your family handling your illness and its change?

How is your family coping with your changing condition?

Are there topics you need help in discussing with them?

Would it be helpful to have us talk to them with you about changes in goals?

Source: Revised from Reference 1.

Transition to Death

When curing is no longer viable, there is the potential for physical comfort and psychological healing instead of cure. Simple presence, listening, and attending to the basic humanity of the dying patient may be one of the nurse's most powerful contributions. Nurses may reduce anxiety and help prepare patients and families just by describing the dying process. As appropriate, the explanation includes the actual physiological and biological process of dying in simple language. The alleviation of pain and symptoms is based on a patient's previously stated preferences regarding desired level of alertness. This may include discussion about the withdrawal of ineffective and/or burdensome medical treatments, including preferences concerning medically administered hydration and nutrition.

Often, a patient considers the meaning of his or her life or performs a life review. This facilitates healing in recognition of personal purpose and meaning, resolution of past conflicts, attaining forgiveness and reconciliation, and achievement of personal integration and inner peace. Additional strategies to help relieve emotional and spiritual suffering include guided imagery, music, reading, and art that focuses on healing.[87] All this may include the collaboration of social work, volunteers, and chaplain colleagues.

The nurse's therapeutic presence with the patient in his or her state of vulnerability and decline can be profound. Here, the nurse consciously and nonjudgmentally listens and bears witness to the patient, encouraging any expression of emotion, doubts, or regrets. The simple acts of visitation, presence, and attention can be potent healing affirmations—a sacramental gesture received by the dying person who may be feeling helpless, diminished, and fearful that he or she has little to offer others. The willingness to demonstrate concern to the patient far outweighs any technique or expertise in the art of listening.

During the dying process, the nurse guides care while promoting healthy bereavement within the family. One critical nursing task is role-modeling for families. Specifically, the nurse demonstrates the art of being present to the dying person. Simply encouraging the family to engage in loving, physical contact, such as holding hands, embracing, or lying next to the patient can be healing. It may help the patient in his or her transition and may help the survivors in their anticipatory grief. For families who want to be present at the time of death, explaining that patients often wait until they are alone to die may prevent the family from feeling a sense of guilt if they are not present at the time of death. Allowing the family to be with the patient after death may help the surviving family members grieve the loss of their loved one.

After death, the nurse offers continued presence, support, and information. The nurse informs the family of the process of certifying death and may assist the family in informing others about the death. Awareness of anticipatory grief and bereavement guides care at this time. Bereaved families are often in most need of having someone to listen to them. Such activities, including telling the story of the loved one's illness, including details of the days and weeks around the death of their loved one, and sharing memories of the loved one, are therapeutic. The nurse may offer information for burial or funeral services as well as grief services. When the family is ready to leave their loved one, the nurse assures respect for the body and explains the process of postmortem care.

Team Communication and Collaboration

Collaboration within an interdisciplinary team is a vital force in working with patients with serious, life-threatening illness. Hanson and Carter describe collaboration as a "dynamic interpersonal process in which two or more individuals make a commitment to each other to interact authentically and constructively to solve problems and to learn from one another to accomplish identified goals, purposes, or outcomes. The individuals recognize and articulate the shared values that make this commitment possible."[117] Good communication ensures better collaboration, ensures comprehensive care, and assures safety and quality.[118] Collaboration enables the sustainability of the team.

However, teams are social systems and have their own dynamics, just as a family does. In effect, the team can be a "work family." With good leadership, role delineation, and flexibility, interdisciplinary teams have the capacity to work well, creating a synergy that promotes positive outcomes.[119] If working effectively, the team identity as a palliative care team supersedes each individual member's discipline. There are necessary qualities to promote effective collaborative teams. First, the participation of all members is essential; the degree of involvement may depend on the issues of the patient and family. Each member's role should be well-defined and respected. Good communication and negotiation are necessary to delineate roles. Second, each team member should have a voice in team processes. Third, the team's mission and goals should be periodically reviewed to assure that all members are working on the same premise. Team members share information and work both independently and together to develop goals. Each team member should be committed to quality care. Fourth, each team member should understand his or her role in patient care and maintain the process of the group. Leadership is shared among team members depending on the task at hand. This means that there must be respect for different styles, trust in clinical competence, and compassion for each other.[117,120] Periodic review of these guidelines will ensure the team's effectiveness and efficiency as a team.

Effective teams promote collaboration through good team communication, team organization and coordination, and competency. This teamwork will be characterized by different environmental and organizational cultures, which dictate the nature of the teamwork as collaborative, deferential, or hierarchical. It is also variable depending on a nurse's role and level of practice. Part of teamwork is the development of working relationships and understanding differing communication styles. This necessitates:

- Recognition of individual team member contributions.
- Respect for and acknowledgment of the competence and expertise of team members.
- Clear definition of roles, responsibilities, and tasks.
- Well-defined reporting structures for both work functions and practice.
- Scheduled communication among team members and meeting times.
- Skilled leadership to manage nurses who are novices, intermediate practitioners, and experts.
- Evaluation processes for quality of care and team effectiveness.
- Psychological and spiritual support for team.
- Ethical and legal resources for the team.
- Respect for patients as individuals.

There is a negative process to teamwork as well. Barriers to effective teamwork include lack of training, hierarchical team structures, organizational rules, and reimbursement issues that cause inherent authority issues.[121,122] Ineffective leadership results in lack of mission and vision. Moreover, team attitude can have an effect on care. There has been an emerging arrogance among palliative care team members that "they know best, are the most caring, effective, and ethical." This can cause negative feelings among other healthcare colleagues, who may feel they are just as caring and committed to patient care.

Poor communication results in poor care, negative outcomes, conflicts, and, ultimately, team demoralization.[118,123] If roles and responsibilities have not been clearly delineated, nurses may feel restrained to broach and discuss certain topics with patients and families, defaulting to the physician who may prefer that these discussions occur at the nursing level. Consequently, a lack of clear roles between nurse and physician can leave patients and families with no communication about their illness, treatment, or prognosis. Ongoing discussions between physician and nurse occur more as a task-focused discussion about patient assessment and response to treatment.[114] Nurses also play an important role in mediating communication between physician and patient and family.[123,124]

Much has been written about how conflict among team members results in bad practices. Eight problematic team behaviors include (1) overwhelming the patient, (2) making the patient part of the team, (3) squelching the voice of individual team members, (4) lack of accountability, (5) team process trumping client outcome, (6) orthodoxy and groupthink, (7) overemphasis on health and safety goals, and (8) squandering of resources. All of these issues can occur at various times within the palliative care team and necessitate good communication and conflict resolution. Examples of these problems include the following:

1. *Overwhelming the patient and family*[125]: This occurs in several ways in terms of timing, information, and presence. One is overwhelming the patient with too much information. An example is when patient and family have just heard difficult news. Then the palliative care or hospice teams enter to "fix" everything, before the patient and family have had time to absorb and integrate the information. Another overwhelming experience is a high ratio of healthcare providers in family meetings. The patient or family may feel outnumbered and disempowered to raise individual issues or concerns.
2. *Making the patient part of the team*[118]: Patients are told that they are part of the decision-making team and are asked for input. The boundaries about what decisions they can or cannot make are ambiguous, especially if they disagree. Moreover, as the patient declines, he or she may not really be able to participate in decision-making.
3. *Squelching the voice of individual team members*: The team may explicitly express that everyone's input is equal when, implicitly, that is not the case. Nonphysician voices may be dismissed, minimized, marginalized, or overturned by physicians when there is disagreement. Another example occurs when, in trying to advocate for a certain unpopular perspective, a team member's opinion may be discounted as "not really understanding the situation," being "no longer objective," or "too close to the situation."
4. *Lack of accountability*: This is often a challenge when there are too many healthcare consultants working with the primary team. Sometimes, with everyone on the palliative care team working on the same issues, no one takes responsibility for the overall care of the patient. In addition, there may be cases where a primary team is detached but asks for input from the palliative care team, but nothing is implemented. Or there may be too many consultants, and the patient receives many mixed opinions with no clear advocate.
5. *Team process having higher value than client outcome*: Healthcare providers often have certain ideas or feelings about what is right or wrong and how things are done. The challenge is to allow an open process to occur and not to limit it to one particular pathway simply because that is the way it is always done. Patients and families are unique in their needs and don't always follow algorithms.
6. *Orthodoxy and groupthink*: A group can become insular and not incorporate new ideas.[126] The team becomes unable to assess itself, and obvious problems are overlooked. In EOL situations, this often happens in relation to the dying process. A nurse may understand that the patient is dying, but other health professionals look for a specific symptom and treat it. The team may think the nurse is "giving up," rather than admit the patient is dying.
7. *Overemphasis on health and safety goals*: This occurs when the care plan itself takes precedence over the patient's needs or choices. This is often seen in the discharge process when the healthcare team disagrees with the patient's lifestyle choices. So, the team resorts to making a plan based on their "safety agenda" rather than a patient's choice.
8. *Squandering of resources*: The needs of patients are missed, especially in the dying phase, resulting in implementation of high-cost interventions with low impact on the patient's overall care.

Teamwork and the Role of the Nurse

Among the team, nurses work the most closely with physicians, either implementing medical orders or following care plans. However, nurses and physicians differ in their communication styles. Nurses tend to be more narrative or qualitative and to emphasize more process and reflection. Physicians tend to be more quantitative and want facts and numbers. Neither style is better than the other; rather, both styles are essential in patient- and family-centered care. Nurses become frustrated with physician communication when physicians seem inattentive or are unwilling to discuss goals of care. On the other hand, physicians report frustration when nurses share disorganized information, include extraneous or irrelevant information, or delay in getting to the point.[127]

The goal of a communication interaction between the nurse and the physician dictates whether reflection or facts are needed. If the contact is about information-sharing, the nurse may need to present details, albeit short and brief. If a treatment change is warranted, the nurse provides supporting evidence. For example, if calling about pain and symptoms, the nurse should know the medications the patient is taking, when they were last taken, and the patient's pain scores, and the nurse should offer a suggested plan. Or, if calling about a patient's change in code status or goals of care, it is critical the nurse offer the rich narrative of the context of the conversation so that the physician may have an effective follow-up conversation.

Quality communication between physician and nurse includes delineating communication roles, reviewing topics to be discussed with the patient and family and by whom, fostering an active communicative role for nurses rather than blindly following physicians' requests, and limiting their own communication with others.[117] When nurses receive authorization or permission from physicians to communicate with patients and families about designated topics or to participate in breaking bad news disclosures, it removes a barrier to nurse communication, which promotes better patient outcomes and patient safety.[118]

Conflict Resolution

Conflict is a situation in which two or more people or parties disagree. This can occur due to different perspectives of care, different patient goals, different values, different ethics, or different role expectations. *Task communication* for teams involves gathering information from each other about clinical care of the patient and family, while *relational team communication* emerges from the general support that team members share regarding workplace stress, coping, and burnout.

Nurses on the front line deal with conflict all the time. This may occur between a patient and a nurse, between a nurse and a doctor, between an advanced practice nurse and a registered nurse, or between two healthcare teams. Conflict is inevitable and healthy for palliative teams, secondary to different perspectives, different experience, length of time in palliative care, and the sense of urgency to alleviate symptoms. If managed well, it helps people look at different perspectives and can allow for creativity and positive movement. If dismissed or ignored, it can breed demoralization and negativity.

Nurses deal with conflict differently depending on their level of practice, practice site, and experience. Often, nurses avoid conflict if they constantly have difficulty in dealing with a team member who will not talk about disagreements. However, in palliative care, the goal should be collaboration in which all problems are discussed and mutual solutions are reached.

Box 5.11 Effective Conflict Negotiation

1. Reflection of the conflict

A. Identify the conflict—the facts

Review:
What happened? Objective data.
What emotions contributed to conflict? Subjective data.
Consider:
What impact has the situation had on you?
How did you contribute to the problem?

B. Identify the goal of conflict resolution

Clarify:
What do you hope to accomplish?
What is the best way to address the issue?
What is at stake for you?

2. Negotiation of the conflict

A. Address the conflict with the other person.

Consider:
When and how is the best way to raise the issue?
How is the best way to achieve the purpose of resolution?

B. Identify each individual's purpose to conflict resolution—the feelings

Review:
Where do you and the other person share purposes?
Where do you and the other person's interests differ?

C. Exploration of the conflict

Discuss:

What is the other person's perspective? Listen to the other individual and explore the story.

What are the other person's feelings? Acknowledge feelings behind story and paraphrase them.

Does the other person understand your perspective? Ask other individual to "listen to you as you share your version of the events and your intentions."

D. Problem solve, with patient's best interest as goal

Invent options to meet each side's most important concerns and interests.

Decide tack of resolution: Avoidance, collaborate, compromise.

Use objective criteria or palliative care standards (NCP *Clinical Practice Guidelines*) for what should happen.

Determine approach for future communication.

Source: Revised Reference 1.

Several methods are available to resolve conflict: negotiation, accommodation, and collaboration. What differentiates these approaches are the perceived power differences. Conflict resolution occurs through a process, see Box 5.11. This involves looking at the facts of a conflict, the feelings of a conflict, and the identity in the conflict.[128] First, the nurse identifies the source of the conflict, reviewing the facts of what happened and what the impact was.

Second, the nurse reflects on the emotional aspect of the conflict—these are the feelings. Then, the nurse addresses the goal of conflict resolution in terms of what she or he hopes to accomplish as it relates to the patient and/or family. Sometimes, this may require looking at the role each provider has at stake and then thinking what is best for the patient.

There are several steps in meeting with a team member about a conflict. Be curious about your colleague's perspective by learning his or her story. In doing so, the two parties share their common purposes and differing interests. Express your views, including statements of feelings, and take the time to listen. This leads to exploration of the conflict and letting each party tell his or her perspective while acknowledging feelings and each party's version of the events. Among the hardest things to learn to say are "I am sorry," "I was wrong," and "You could be right." It is not necessary for the nurse to feel pressured to agree instantly. Rather, it is important to discuss the range of the issues. Problem-solve together, with the common goal being the patient's well-being, and decide on a tack of resolution.

Conclusion

Communication in palliative nursing is the essential tool by which nurses deliver care. Effective communication sets the foundation on which the care plan is established and guides the care. Nurses need to seek education and practice communication skills in situations specific to patients with serious illness.[129] The art of nursing communication is based on the use of physical presence, listening, silence, and therapeutic presence. This is enhanced through emotional intelligence. The science of nursing communication involves skills in verbal and nonverbal communication and the application of communication strategies to promote effective, quality care. Patient- and family-centered care necessitates effective nurse communication to impart communication, gather information, and provide a therapeutic presence. Communication is essential in team collaboration and resolving conflict. Nurses have a direct role in difficult conversations ranging from information-sharing about diagnosis and treatment, counseling about EOL choices, determining values and preferences, supporting patients and families in bad news conversations, and facilitating transitions to palliative and hospice care.

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CHAPTER 6

Advance Care Planning

Shigeko Izumi

Key Points

- Advances in medical technology have made extension of life possible and various end-of-life (EOL) treatment options available. However, patients frequently lack decision-making capacity at the time when they need to make EOL decisions for themselves.
- Family members and healthcare providers often do not know what EOL care patients want and experience psychological distress during and after making EOL decisions for the patient.
- Advance care planning (ACP) is a process that facilitates patients making plans for EOL care for the time when they are not capable of making their own decisions. The plan is intended to be shared with family members, significant others, and healthcare providers to guide EOL decision-making that honors the patient's values, goals, and preferences of care.
- ACP is a central tenet of person-centered care. Building systems to assist all patients with ACP and honor their values as standard practice is urgently needed.

Introduction

The goal of healthcare is to provide the care patients want to receive.[1] However, providing the care that patients want is difficult if the care team does not know what the patient's preferences are. Advance care planning (ACP) is a process to plan for future healthcare decision-making so that family members, surrogate decision-makers, and healthcare providers can know and honor persons' preferences when they become unable to make their own decisions or express their preferences. While ACP is increasingly recognized as an essential component to provide patient-centered and high-quality end-of-life (EOL) care, how to facilitate and use ACP to guide better EOL care remains challenging.[2] This chapter provides a contextual background for ACP, definitions and processes of ACP, and the nurse's role in ACP.[3]

Background

Advances in medical technology have made extension of life possible and various EOL treatment options available.[2] To date, when patients face life-threatening illness or injury, several treatment options may be available including cardiopulmonary resuscitation (CPR), ventilators, or medically administered nutrition to extend life; experimental treatments aimed at achieving a cure; and palliative care focusing on comfort and improving quality of life. A large national survey of Medicare beneficiaries shows that 86% of people prefer to spend their last days at home rather than in a hospital and that they do not want life-prolonging treatments that make them feel worse.[3,4] Although the proportion of people who die in hospitals has gradually declined and the use of hospice services has increased in recent decades,[5] more than one-third of decedents still died in a hospital in 2015, indicating a gap between what EOL care people want to receive and what they actually received.

Studies also show increases in intensive care unit (ICU) use in the last 30 days of life and increases in the number of healthcare transitions in the last few months of life.[6] Multiple healthcare transitions, including in and out of the ICU during the end stage of their lives, imply that patients' health status fluctuates during this time, and they have to make multiple healthcare decisions as to where and what kind of care they receive through the last few months of their lives. A typical course of care transitions in EOL care is that a patient is admitted to an acute care setting for exacerbation of illness; is transferred to ICU for intensive treatments as his/her condition worsens, where s/he potentially faces limited treatment options or becomes too ill to endure treatment, thus changing the focus of care; and is discharged to home or a similar environment to receive comfort care.[7] Transitions in treatments and sites of care as their condition changes is common and appropriate if each decision reflects the patient's preferences and goals at that time. However, because the default medical treatment for seriously ill patients is "do everything to save a life," some of the transitions that happen in the last few months, weeks, or days of their lives may be driven by this default and may not reflect these patients' true preferences based on well-informed decision-making.[7,8] To choose treatments that may be different from the default treatments that healthcare providers assume, patients have to actively engage in the decision-making and express specific preference for the chosen treatment. Unfortunately, approximately 70% of patients needing to make EOL care decisions are unable to participate in the discussion and lack the decision-making capacity or ability to express their preferences.[9,10]

Therefore, it is important that family members and healthcare providers know what is important for patients and what EOL care they want to receive while the patients are still capable of expressing their preferences. Unfortunately, family members who are expected to assume the surrogate decision-maker role infrequently have prior conversations with the patients and know their preferences or values. When family members make decisions for critically ill patients without prior conversations, they often struggle and experience strong emotions such as guilt and regret during and after rendering a decision, which contributes to long-lasting psychological suffering.[11–13] Having ACP conversations with patients prior to decision-making is shown to be associated with less decisional conflict and less psychological burden for surrogate decision-makers.[14]

For patients to have an opportunity to express their preferences for EOL care while they are capable of decision-making, the Patient Self-Determination Act (PSDA) was passed in 1990. The PSDA requires hospitals, nursing homes, and other healthcare institutions to ask all patients whether they have advance directives and to provide information about advance directives upon their admission to the facility.[15] Although the PSDA was intended to educate patients about healthcare decision-making rights and encourage them to make the decision and document it in a legal form, advance directive completion rates actually hover between 20% and 50%,[16–18] and completion of advance directives does not necessarily promote better care at the end of life.[19,20]

Patients might have advance directives, but often no one knows that an advance directive exists or it cannot be located when needed.[21] Some advance directives are written using legal terms and are difficult to understand, particularly for persons with low health literacy, with a different primary language, or in poor health.[22,23] Treatment preferences that are based on hypothetical scenarios may not reflect what the person wants in the actual situation.[20] Broad value statements such as "maintain dignity" can be too general to guide concrete treatment decisions in specific situations.[24] Despite the well-intentioned enactment of the PSDA, situations where family members and healthcare providers have to make difficult EOL care decisions without knowing the patient's preferences continue to exist.

The Institute of Medicine (IOM) report *Dying in America*[2] examined the issues in EOL care in the current healthcare system and identified a lack of clear communication about death and dying and candid discussions to learn about a patient's values and preferences as a barrier for quality EOL care. Their recommendations include improved clinician–patient communication and ACP as essential components to improve EOL care.

Definitions of Advance Care Planning

The IOM report defines ACP as "a process of discussion of EOL care, clarification of related values and goals, and embodiment of preferences through written documents and medical orders. This process can start at any time and be revisited periodically, but it becomes more focused as health status changes" (pp. 122). More recently, consensus definitions of ACP were developed by multidisciplinary international ACP experts[25,26] (see Box 6.1). Key points common to these definitions include:

1. ACP is a process, not a one-time event.
2. ACP includes discussions to understand and share values, goals, and preferences of the person for future medical care.
3. ACP can start at any age or stage of health.

The concept of ACP has been evolving. Sudore et al. observed a shift in definition of ACP in the past few decades, and disagreements about what ACP should entail exist among ACP experts.[25] The observed disagreements include whether to focus on conversations versus a written document, treatment preferences versus a patient's values, and who should be included in the process.

Box 6.1 Consensus Definition of Advance Care Planning

Advance care planning (ACP) is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness.

Sudore RL, Lum HD, You JJ, et al. Defining advance care planning for adults: A consensus definition from a multidisciplinary Delphi panel. *J Pain Symptom Manage.* 2017;53:821–831.

Advance care planning enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate.

Rietjens JAC, Sudore RL, Connolly M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol.* 2017;18(9):e543–e551.

Conversation Versus Documentation

In the consensus definition (Box 6.1), conversations are highlighted as a critical part of ACP to understand the patient's values and preferences, while documentation of the patient's values and preferences (e.g., advance directives) is an important strategy or a tool to ensure that the patient's preferences are clearly communicated to family members, providers, and across settings. Patients having conversations with their family members and significant others create a space where patients can reflect and let others know and understand what is important for them. In conversations, others can ask the patient to clarify what he or she means, and then family members are left with a deeper understanding of what and why certain choices are important for the patient. Such dialogue could guide decision-making in a situation where documentation is lacking or where such decisions were not anticipated.

Documentation of the ACP conversations in the patient's health record to provide the context of patients' decisions is recommended. Documentation of patient's values and preferences with or without conversations is also possible. Some programs encourage patients to write a letter or create a video letter to their healthcare providers and loved ones and add it to the patient health record; this is another way to communicate preferences to others (see https://med.stanford.edu/letter.html). While conversations and letters are powerful ways to communicate values and preferences, formal documentation of patient's instructions for EOL care, such as advance directives, also should be encouraged. Despite some deficiencies in legal documents, having a standardized form that concisely communicates a patient's preferences in emergency situations is valuable. Healthcare providers seeing the patient when EOL care decisions need to be made are often not the same providers who know the patient and were involved in the ACP conversations. Having a formal document outlining a patient's preferences and identifying key decision-makers assists healthcare providers who may be unfamiliar with the particular patient. The providers can then contact and involve the right persons in the decision-making and will be more likely to reach the right decisions for the patient.

Treatment Preferences Versus Patient's Values

Another area of disagreement is knowing and focusing on patients' preferences for specific medical treatments or their life goals and values. While patients' expressed preferences for specific treatments (e.g., CPR, tube feedings) are helpful, their preference for the treatment may be different in a hypothetical scenario when compared to the actual situation. In a specific context where a decision needs to be made, available treatment options may vary. Experts recommend that ACP conversations should start with overall personal life goals and values, such as what is important for them; then these values should be translated into more specific discussions about medical treatments as their stage of illness progresses and more specific treatment decisions need to be made.[25,27]

Who Should Have Advance Care Planning?

There are discussions about whether ACP should include healthy adults or only seriously ill patients. Concern exists in some experts that a healthy person with no experience with serious illness may have little perspective from which to make ACP decisions. Therefore, they suggest that healthcare providers should focus their ACP efforts on patients with serious illness only. Yet identifying patients with serious illness who should have ACP is often difficult and unreliable.[28] One of the reasons that many patients admitted to ICU have never had prior ACP conversations despite their serious illness is that clinicians often do not recognize the seriousness of the illness and the need for ACP until it is too late. Furthermore, even healthy persons could suddenly face EOL decision-making due to accident or acute illness and could benefit from having a plan. The goal of ACP is not to make definitive decisions about EOL care at the moment, but to learn about patients' values and preferences so that the conversations and/or documents could guide future decision-making when an unfortunate event happens. The current definition of ACP has broadened to encompass engagement with people for future decision-making regardless of their age or stage of illness.

Another issue regarding ACP's target population is whether ACP should focus on patients or surrogate decision-makers. A goal of ACP is that a person with decision-making capacity reflects on his or her life values and goals and makes a plan for their EOL care. Because patients are often not able to make their own decisions at the end of life,[9] ACP should include identifying a surrogate decision-maker, communicating the plan to that person, and preparing them to make the necessary decisions. Even when patients retain their decision-making capacity at the end of life, those who have had opportunities to reflect on their life values and discuss them with their loved ones are better prepared to clarify care preferences as they face important decisions. Therefore, the focus of ACP is preparing both patients and surrogate decision-makers through engagement in ACP and communicating the values and preferences that will guide the decisions.

The last area of consideration is who should facilitate ACP. In the past, ACP conversations were mostly limited to those patients with life-threatening illnesses, and conversations often included the delivery of poor prognosis related to the patient's illness. Therefore, physicians historically assumed the role. With recent ACP definitions that have broadened the process to include healthy persons or those with chronic illness and to focus more on personal goals and values rather than medical treatments, there are opportunities for other healthcare team members to facilitate continuous ACP conversations across the illness trajectory. Primary care providers who see patients at their wellness visits; nurses consulting for chronic illness management; and nurses, social workers, or chaplains who are admitting and caring for patients across acute care settings can all facilitate these conversations and elicit what is important for patients and help them communicate these values to their families and healthcare providers. Currently, licensed independent providers (LIPs) are able to bill for ACP conversations using a billing code for the Center for Medicare and Medicaid Services.[29] Although non-LIP professionals' time for ACP facilitation is not billable, there is no restriction on or statement about who can and cannot have ACP conversations with patients.

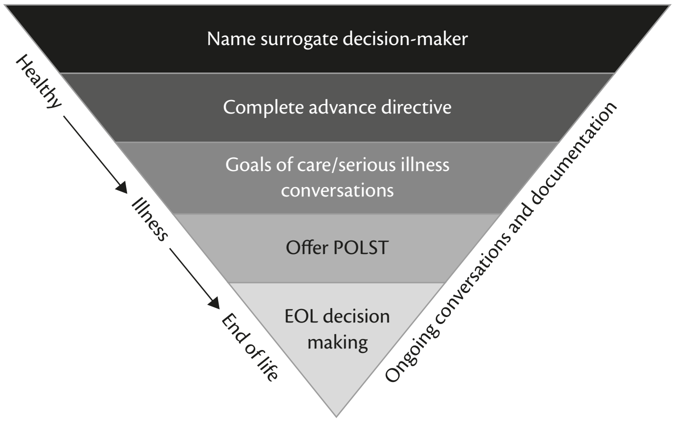
Name surrogate decision-maker
Complete advance directive
Goals of care/serious illness conversations
Offer POLST
EOL decision making
Healthy
Illness
End of life
Ongoing conversations and documentation

Figure 6.1 Continuum of advance care planning.
Source: Reference 30. Created by Shigeko Izumi and Erik Fromme. Reprinted with authors' permission.

Process, Tools, and Strategies for ACP

The ACP conversation should start well before the time of actual EOL decision-making and be revisited as the person's health and life values change. As the person becomes seriously ill and gets closer to the EOL stage, the focus of ACP conversations could be narrowed and specific. Because these conversations happen over time, on multiple occasions, it is rare for individual clinicians to participate in the evolution of ACP over several years of the person's life. Figure 6.1 is a model describing the continuum of ACP along with changes in health status.[30] The model illustrates ACP activities across a continuum from health to illness to end of life and the topics that clinicians could address with the person depending on the stage of his or her health. In the following section, the process of ACP along with the continuum of the ACP model is described with Case Studies illustrating issues.

Case Study 1: Healthcare Professionals Did Not Know Who Would Be the Surrogate Decision-Maker

A twenty-four-year-old obstetric patient was admitted to a hospital for elective caesarean section. During the procedure, she experienced massive blood loss necessitating an emergent decision about hysterectomy. Because the patient was unconscious and a decision needed to be made, the physicians consulted with the woman's mother who was present in the waiting area and was listed as her "emergency contact" in the electronic health record. The mother consented for the hysterectomy, and the procedure was completed.

After the surgery, the patient was upset because she wanted her fiancé, with whom she is going to make future family plans, to make the decision, not her mother. Asking patients about their surrogate decision-makers was not a requirement before a procedure in this hospital, and the surrogate decision-maker section in the health record was left empty. According to the state law and the hospital's policy, if patients do not name the surrogate decision-maker, a default surrogate decision-maker is determined in order of (1) spouse, (2) adult child, (3) parent, or (4) siblings. In this case, the patient did not have a spouse or adult child, and her mother was the legally correct surrogate decision-maker.

Naming the Surrogate Decision-Maker

Because acute illness or injury could happen to anybody, it is recommended that healthcare providers ask all patients to name and document a surrogate in the patient's health record. Even healthy patients admitted to a hospital for elective surgery may need someone to make decisions for them while they are under anesthesia. Case Study 1 is not about EOL decision making, but it is an example of how not knowing the patient's surrogate decision-maker could result in less than optimal decisions that were not concordant with the patient's preferences. Assisting persons in appointing a surrogate decision-maker becomes especially important with a diagnosis of life-limiting or chronic illness that is expected to cause declining mental health. Alzheimer's disease is an example of a chronic illness where an individual may lose the ability to make informed decisions. It is important to have conversations to name a surrogate as soon as possible, while the person can participate in the conversation.[31]

A surrogate decision-maker is someone patients trust to make healthcare decisions and to speak for them in the event they are unable to. A surrogate decision-maker is sometimes called a *healthcare proxy*, a *durable power of attorney (DPoA) for healthcare*, a *healthcare agent*, or *healthcare representative*. Most of the states and many healthcare organizations have policies about the surrogate decision-makers for incapacitated patients. If a patient does not appoint a surrogate before he or she loses capacity, decision-making falls to the patient's next of kin according to state law, usually in the following order: spouse, adult children, parents, adult siblings, adult grandchildren, or close friends. Patients can name their surrogate decision-makers out of order of the state law or name someone other than next of kin, but this needs to be documented in a legal form, such as an advance directive or healthcare proxy, to be valid. In Case Study 1, the patient's mother was not only the emergency contact person and present in the waiting area, but she was also the legally valid next of kin to be the surrogate decision-maker. Because the patient was not asked and did not name her fiancé as her surrogate decision-maker in a legal document, her fiancé was not contacted when the decision had to be made. Today's family structure and personal relationships are diverse and complex. If the surrogate decision-maker a patient trusts is not the conventional next of kin, it is important to advise the patient to complete his or her advance directives in order to legally name the surrogate decision-maker.

A surrogate decision-maker is the person who will speak and make decisions for the patient when he or she is unable to speak for him- or herself. Speaking up and making healthcare and life-support decisions in a high-stress situation is very difficult; it is beneficial to guide patients on how to choose the right surrogate decision-maker. The surrogate decision-maker should be someone who:

- You can trust to speak for you
- You can talk to and who knows about your values, goals, and preferences
- Is willing to accept the role
- Is able to follow your wishes
- Is able to speak up on your behalf
- Is able to make decisions in stressful situations

Brochures and other materials guiding the selection of the right surrogate decision-makers are available at the Conversation Project website (https://theconversationproject.org/wp-content/uploads/2017/03/ConversationProject-ProxyKit-English.pdf); the next section provides more information on the Conversation Project.

Complete Advance Directives

Advance directives are written documents that describe a person's treatment preferences in EOL care and identify a surrogate decision-maker. Advance directives are legal documents in most states. In some states, surrogate decision-makers are appointed using a special form (e.g., healthcare proxy, healthcare power of attorney) separate from an advance directive form. The section for treatment preferences in an advance directive is sometimes called a "living will," where persons express what life-sustaining treatment (for example, CPR, tube feeding) they would or would not want in terminal conditions. It is recommended that all adults who have decision-making capacity complete an advance directive for the time when they may become unable to make decisions.

Unfortunately, completion of an advance directive is difficult for many people because it is written in ambiguous and nonspecific medical and legal terms. In addition to the difficulty posed by the high literacy level of advance directive forms, thinking and making decisions about future EOL care can be an overwhelming task. Although completion of an advance directive does not require involvement of healthcare professionals, many persons find assistance or guidance from healthcare professionals helpful. Resources are available to guide the public in having these conversations and formulating advance directives. The Conversation Project started as a grassroots movement to promote EOL care conversations at the kitchen table so that individuals could let their loved ones know about their values and preferences. In collaboration with the Institute for Healthcare Improvement (IHI), the Conversation Project provides various materials to support these conversations among loved ones (https://theconversationproject.org/). Another good online resource is *PREPARE for Your Care,* a web-based guide that helps people plan for and make decisions about their future care. *PREPARE* is based on behavior change theory and is designed to engage older adults and persons with diverse cultural background and low-literacy levels in ACP.[32] Step-by-step video instructions and an easy-to-read advance directive are provided at this website. The organizers of the site document significant increases in the number of people accessing ACP and its documentation online[33]; see https://prepareforyourcare.org/welcome.

It is not only important to complete an advance directive, but it is also essential to document where the advance directive can be found when needed. Keeping advance directives in a safety vault or lawyer's office without telling anybody does not serve the purpose. Persons who have completed advance directives should be advised (1) to give copies to their surrogate decision-makers and healthcare providers, (2) inform their families and close friends about their surrogate decision-maker and wishes, (3) keep a copy of the advance directive where it can be easily found, and (4) take a copy with them if they go to a hospital or nursing home. ACP is an ongoing conversation, and completing an advance directive is not a one-time event. People change their minds as their health and life circumstances change. The advance directive should be revisited and revised as life goals and values change.

Having a Goals-of-Care Conversation

When patients become ill, more focused conversations between patients and healthcare professionals need to occur. The aim of such conversations is for healthcare providers to understand patients' goals and values and align medical treatments with them. Prior reflection, conversations with families, and completion of advance directives would be helpful to prepare for these conversations. Yet thinking about hypothetical EOL situations and planning for immediate or near future decision-making about medical treatment carry different weights and require different approaches.

There are two similar and overlapping yet slightly different types of conversations at this stage. One is a conversation that leads to shared decision-making to select the right treatment at any stage of illness. This conversation does not need to be about EOL care. It could occur when a patient and healthcare providers discuss and decide what treatment option is appropriate for the patient who is newly diagnosed with early-stage cancer or for heart failure that is gradually progressing. The underlying tenet is that patients should receive care that is consistent with their goals and values at all times. Thus, each treatment decision should be made based on candid discussions that ensure that the goals of treatment align with the patient's goals and values at the moment.

Another type of conversation is one with seriously ill patients, for whom a poor prognosis is looming and revisiting the alignment of current treatment goals and the patient's goals is needed. This is comparable to the conversation traditionally called ACP, goals-of-care conversation, delivering bad news, or EOL conversation. This conversation is usually triggered by clinicians when they see a patient approaching end of life and have concerns that current treatment may or may not align with that patient's quality of life. A limitation of this approach in preparing patients for better EOL care is its reliance on clinician judgment to identify the need and take action. Clinicians so focused on treating disease may not recognize a patient's overall decline. They may be aware of the need for a conversation, but they may be afraid to talk about death and dying and therefore avoid the conversation.[34–37] Because of these reasons, the conversation may occur too late, when patients are in crisis or unable to participate in the discussion.[38,39]

There are growing efforts to train healthcare providers to have earlier goals-of-care conversations with their patients. Vital Talk (vitaltalk.org) and the Serious Illness Care Program (https://www.aradnelabs.org/areas-of-work/serious-illness-care/) are examples of programs that provide evidence-based conversation skill training and guides for healthcare providers. A key issue in goals-of-care conversations that meaningfully contribute to planning for quality EOL care is knowing patients' goals, values, and wishes and aligning treatments to meet these personal values. Healthcare providers are trained to make judgments about the best treatment in the situation and provide those treatments, but they sometimes fall short in ensuring that the medically appropriate treatment matches the patient's values. Vital Talk and the Serious Illness Conversation Guide provide framework, strategies, and some useful language to elicit a patient's values and goals and to make shared decisions for treatments that align with a patient's values, particularly when the patient is seriously ill and has a limited prognosis. Although many of these training programs have been targeting licensed independent providers (e.g., physicians, nurse practitioners, physician assistants) whose scope of practice includes prognostication and medical treatment decisions, there is an increasing interest to expand this training to clinician groups that have the skills to assist patients and facilitate the conversations.

The healthcare system is transitioning from a traditional biomedical model where healthcare providers make healthcare decisions from a position of authority to a patient-centered care model where care providers and patients jointly make treatment decisions. When the shared decision-making becomes the norm for any treatment decision beginning in the early stage of illness, the serious illness conversation may become a mere extension of prior conversations and be less threatening for both patients and clinicians.

Medical Order for Life-Sustaining Treatment

The aim of this step is to translate patients' preferences about life-sustaining treatments into a standing medical order. When people reach a critical stage in their illness such that healthcare providers would not be surprised if they die within a year, it is helpful to have a standing medical order that instructs other healthcare professionals about what treatment should be provided in an emergency or outside-of-hospital settings. The Physicians Order for Life Sustaining Treatment (POLST) (also called Medical Order for Life Sustaining Treatment [MOLST] in some states) is a portable medical order form that prescribes life-sustaining treatments that patients would want during a medical crisis and helps to avoid the provision of treatments that patients would not want (http://polst.org/about-the-national-polst-paradigm/what-is-polst/). The POLST should be portable and stay with patients. If patients live in their home, the POLST should be posted in a visible location (e.g., refrigerator door). If patients are transported to a nursing home, emergency department, or hospital, the POLST should go with the patient.

A POLST paradigm is adopted in many states. Although details may vary slightly by state, the POLST form usually includes preferences for CPR, different levels of medical interventions (comfort measures only, limited treatment, or full treatment), and signature by ordering healthcare provider. The POLST form should be completed based on informed, shared decision-making between patients and healthcare providers. The POLST form must be signed by a healthcare provider who is accountable for the medical orders. State law identifies which healthcare providers are authorized to sign medical orders. In Oregon, where POLST was first developed, there is a state-wide POLST registry where all POLST forms are sent. Through this registry, healthcare staff can access a patient's POLST online in an emergency.

Table 6.1 Differences between advance directives and Physicians Order for Life-Sustaining Treatment (POLST)

Advance directive	POLST
For anyone 18 years or older	Most appropriate for those who are frail or seriously ill
Legal document completed by patient with instructions for end-of-life treatments	Medical orders for life-sustaining treatments based on discussions between a patient and a healthcare provider
Does not guide emergency personnel because it is NOT a medical order	Provides medical orders to emergency medical personnel
No need for healthcare provider's signature	Needs healthcare provider's signature
Appoints a surrogate decision-maker Needs patient's and surrogate decision-maker's signature	Does not identify surrogate decision-maker Patient's and surrogate decision-maker's signature is recommended but not required
No registry available Patients and/or family members need to produce it when needed	POLST registry may be available POLST stays with patient

Because it is a medical order, POLST should be followed by emergency medical personnel outside of hospitals as well as any healthcare professionals in other settings. Both advance directives and POLST are useful tools to communicate and document patients' values and preferences for EOL care. Yet there is some confusion between the two. Table 6.1 summarizes the differences between advance directives and POLST.

Use of Advance Care Planning in EOL Decision-Making

The purpose of the ACP is to ensure that a patient and his or her loved ones know what is important for the patient and what treatment he or she wants to receive at the end of their life. When the person becomes not able to make his or her own decisions, those present (family, friends, and the healthcare team) feel prepared to make the best decision honoring the person's values and preferences. All prior conversations between the person and his or her family and healthcare teams—and any documentation of these conversations, such as naming surrogates, advance directives, goals-of-care conversations, and POLST—will guide persons, family members, and healthcare providers to make EOL care decisions. The last stage of ACP (the bottom apex of the continuum of the ACP model in Figure 6.1) is not planning, but using the plan developed through the process. When healthcare professionals see a patient who is seriously ill, the automatic response is to save the patient's life. But if that is not what the patient wants, doing everything to save the patient's life may not be quality care for that patient. Some healthcare providers equate providing life-extending treatment that does not match with a patient's wishes to medical error. In order to provide the care that patients want to receive, healthcare professionals need to inquire as to whether the patient has ACP and elicit the patient's wishes instead of assuming the patient wants to live longer. The healthcare professional's role is to work with patients and surrogate decision-makers to make the best decision that honors a patient's values in a given situation.

Roles and Responsibilities of Nurses in Advance Care Planning

The American Nurses Association's position statement[1] asserts that nurses are responsible for facilitating the process of informed healthcare decision-making for patients. ACP is a central tenet of person-centered care, and it provides a way to facilitate informed, shared decision-making for EOL care by assisting patients to reflect and communicate their values.

Case Study 2: Advance Care Planning at Hospital Admission Make a Difference

Nurses in a bone marrow transplant (BMT) unit in an academic medical center were conducting a quality improvement project that asked all patients to name a surrogate decision-maker and encouraged them to have advance directives completed within 48 hours of admission to their unit. On admission, a patient with a new diagnosis of blood cancer told the nurse that she wanted her two best friends to be her surrogate decision-makers instead of her family. She explained that her ex-husband was the primary support but not the decision-maker, and her daughter was using substances and was unreliable. The nurse involved a social worker to assist this patient to complete an advance directive appointing her friends as surrogate decision-makers.

Two weeks later, this patient was dying unexpectedly in the ICU. At her bedside were only her ex-husband and her daughter who wanted "to do everything." ICU nurses saw the advance directive and contacted the social worker in the BMT unit, and the social worker spoke with the patient's surrogate decision-maker friends by phone. The surrogate decision-makers had previous conversations with the patient about the EOL care she wanted to have and did not want to have. The decision was made to not intubate and not continue aggressive life support treatments. The patient's ex-husband and daughter were upset that they were not named as decision-makers, but the patient's wishes were honored at the end of life because she had talked about these issues and had the directive in place. This patient died 5 minutes after aggressive treatment was stopped, and she was comfortable as she died with her daughter holding her hand.

As described in prior sections, ACP should happen across the various stages of a patient's health, and all patients that nurses encounter in their practice should have the opportunity to plan and prepare for future health situations. In Case Study 2, the patient was not expected to die during this hospital stay, but nurses asked who the patient trusted to be her surrogate decision-makers and encouraged her to have conversations with her chosen surrogates. The BMT unit nurse's early ACP conversation with the patient to plan for EOL decision-making enabled the ICU care team to provide the care the patient wanted. Nurses are responsible for educating their patients about the importance of ACP and assisting them in making a plan that is appropriate for them. Nurses working in primary care settings should educate patients who come in for annual wellness visits about the importance of identifying surrogate decision-makers and encourage them to start these conversations with their families in case of an unpredictable event, such as an accident. Reviewing ACP can be a routine health maintenance process, one similar to immunizations. Nurses seeing patients with chronic illness can assist them in thinking about what is important for them and encourage them to have conversations with healthcare providers to make informed shared decisions about treatments that are consistent with their values.

When patients are making a plan for future treatment by completing advance directives or POLST, nurses can explain what the potential implications of CPR or tube feedings are and assist them in having meaningful conversations with healthcare providers and in making well-informed decisions. When a patient and his or her family are in a situation where EOL care decisions need to be made, nurses should advocate for the patient by directing the healthcare team's attention to the patient's values, goals, and preferences and ensuring that the patient receives the care he or she wants.[40]

In addition to their responsibilities as registered nurses, advance practice nurses need to be familiar with the process of ACP that is appropriate to their specialty role and patient population. The specialty role may include communication, documentation of information and forms, and possibly how to bill for the ACP conversation to make the ACP facilitation practice sustainable in their practice. Additional training to facilitate serious illness conversations, including prognosis and treatment decisions, may be needed. Models describing the process of ACP and tools introduced in prior sections could be used to plan and implement ACP in the advance practice nurse's role as well.

Conclusion

ACP is gaining recognition as an essential component to provide quality EOL care, and both the public and healthcare professionals are increasingly aware of its importance. While the concept of ACP is broadly accepted as good practice, implementation of ACP in routine practice in many care settings remains challenging. In addition, evidence showing what and how ACP improves the quality of care that patients receive is still limited.

Essential components of ACP such as knowing a person's values, goals, and preferences; facilitating conversations with patients, families, and healthcare providers for informed shared decision-making; and advocating for provision of care that is consistent with a patient's values are core principles of nursing. Nurses, particularly palliative nurses who have expertise in these areas, take a leading role in ACP by educating patients, families, and other healthcare professionals and advocating for its implementation in everyday practice.

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SECTION II

Symptom Assessment and Management

CHAPTER 7

Interdisciplinary Palliative Care Teams

Specialists in Delivering Palliative Care

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Key Points

- Palliative care attends to the physical, psychological, social, and spiritual domains of quality of life, providing specialty care for patients with serious illness and their families.
- Palliative care is provided by an interdisciplinary team (IDT) whose members are palliative care specialists able to meet the complex, multidimensional needs of patients and families facing serious illness.
- The roles of the palliative care team members are unique within their specialty; however, there are many instances in which team roles may overlap.
- Four major models of team-based palliative care—inpatient consult teams, ambulatory care teams, community-based palliative care teams, and hospice teams—provide interdisciplinary expertise in the delivery of quality palliative care across the disease trajectory of serious illness.
- A highly functioning palliative care team requires that its members share the team's mission and vision, share leadership and accountability, and trust and respect each other.

Introduction

Palliative care is interdisciplinary care (nursing, medicine, social work, chaplaincy, and other specialties as appropriate) that specializes in assessment and management of physical, psychological, social, and spiritual needs of patients and families dealing with serious illness.[1] It focuses on improving the quality of life (QOL) of patients and families and is initiated ideally at the time of a serious illness diagnosis and provided concurrently with disease-oriented treatment, across the disease trajectory.[1,2] Members of the palliative care team work not as individual disciplines, but as a team, as a whole, with a shared vision and mission to improve patient and family QOL.[3]

Over the past two decades, the United States has witnessed a remarkable growth in palliative care services with the expansion of four major care-delivery models.[1,4,5] The most frequently utilized model of palliative care was initiated in the early 1990s in acute care settings as a consult service for those hospitalized with serious illness. This inpatient consult service provided specialty care in the hospital setting, with or without a palliative care unit.[6] In the mid-2000s, research began to demonstrate that patients benefit from having specialty palliative care services available in ambulatory care units, and this emerged as a second model for palliative care.[7,8] These outpatient services were started in oncology clinics across the country.[7,8] Now, many more specialty outpatient departments, such as cardiovascular clinics and neuromuscular clinics for diseases such as Parkinson's disease and amyotrophic lateral sclerosis (ALS), are collaborating with ambulatory palliative care to provide outpatient services. Most recently, a third model of palliative care delivery, community-based palliative care teams, has arisen out of a need to focus on the delivery of palliative care to those in the home, including assisted living and long-term care facilities.[9] Community-based palliative care can be delivered in person or via telehealth in areas of limited access.

The fourth model of palliative care delivery is hospice care.[10] Hospice care is the initial model of team-based palliative care, one that began in the United States in the late 1970s in response to a need to improve care to patients at end of life and their families. It is regulated by federal programs (i.e., Medicare, Medicaid, and Veterans Affairs) in the United States, as a separate system of care for those with a life-expectancy of 6 months or less who choose to forgo disease-focused treatments.[1,11] Hospice always delivers palliative care; however, palliative care is not the equivalent of hospice care. The confusion between these two services has made it challenging to educate patients, families, and other healthcare providers on the differences (Table 7.1).[1]

Table 7.1 Models of palliative care

	Inpatient consult service	Ambulatory palliative care	Community-based palliative care	Hospice care
Team	Interdisciplinary team: physician, nurse; access to social work (SW) and chaplaincy as available and as needed	Interdisciplinary team: Physician, nurse; access to outpatient SW, chaplaincy as available and as needed	APRN or physician: Requests are made for additional team members, if available	IDT including physicians, nurses, SW, chaplain, volunteers, nursing assistants, and bereavement coordinators
Eligibility	From diagnosis of serious illness across disease trajectory	From diagnosis of serious illness across disease trajectory	From diagnosis of serious illness across disease trajectory	Patients of all ages who have a prognosis of survival of 6 months or less if the disease follows its usual course; must forgo Medicare coverage for curative treatment related to the terminal illness
Delivery site	Consult services go to patients and families in the ICU, ER, and hospital units	Outpatient clinic setting; can be imbedded in specialty clinics (heart failure) or in a designated palliative care clinic; ideally, space is allocated for conferencing with patients and families	In patient's home, including assisted living, long-term care facilities; may also use telehealth resources	Most hospice care is delivered in the patient's home; other sites include assisted living, long-term care facilities, residential hospice facilities, inpatient hospice units or hospice-contracted inpatient beds
Reimbursement	Physician and APRN bill insurance or Medicare Part B for inpatient care	Physician and APRN bill for outpatient specialty visit	Physician and APRN bill insurance for specialty provider care	Team care is bundled and covered by Medicare hospice benefit or commercial insurance hospice benefit, modeled after Medicare; Medicaid coverage varies by state

APRN, advanced practice registered nurse; ER, emergency room; ICU, intensive care unit.

The focus of this chapter is on the interdisciplinary team (IDT) that provides specialty palliative care regardless of the model of care delivery. The chapter emphasizes each team member's essential role in the provision of quality palliative care and how the team as a whole collaborates with the patient and family to ensure that the patient's goals of care are respected and honored. A complex case study will demonstrate the roles of the team and their unique contributions to quality palliative care for a patient with ALS and her family. This chapter will also discuss the four major models of palliative care in more depth and the current benefits and challenges of each. An introduction into the development of a palliative care team and the importance of maintaining a healthy, functional team will be presented at the end of the chapter.

The Interdisciplinary Palliative Care Team

According to the National Consensus Project (NCP) guidelines,[9] palliative care "provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness and their families. Palliative care may begin early in the course of treatment for a serious illness and may be delivered in a number of ways across the continuum of health care settings, including in the home, nursing homes, long-term acute care facilities, acute care hospitals, and outpatient clinics. Palliative care encompasses hospice and specialty palliative care, as well as basic palliative care."[9]

Within Domain 1 of the NCP *Guidelines for Quality Palliative Care*, Structure and Processes of Care, there are ten guidelines, each with its own criteria, that relate directly to the palliative care delivery model and the IDT.[9] These guidelines are important not only for the development of the palliative care team, but also for sustaining the IDT by evaluating their ability to meet these criteria on a regular basis and revise processes as necessary. Quality structure and processes of care are critical to the sustainability of the palliative care IDT. Communication and collaboration within the team is essential. It is not unusual for there to be some overlap in the roles of these IDT members, but collaboration and communication among team members ensures a well-functioning team and improves the overall patient and family outcomes.

Role of the Team Members

Chaplain

According to Domain 5 of the NCP *Guidelines for Quality Palliative Care*,[9] spiritual care is an essential component of a palliative care team. Unfortunately, less than half of the teams listed in the 2015 National Palliative Care Registry had a complete core of team members, including chaplains.[12]

Spirituality is "recognized as a fundamental aspect of compassionate, patient and family-centered palliative care. It is a dynamic and intrinsic aspect of humanity through which individuals seek meaning, purpose, and transcendence and experience relationship to self, family, others, community, society, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices."[9] Although it is the responsibility of all IDT members to recognize spiritual distress and attend to the patient's and the family's spiritual needs within their scope of practice, the palliative care chaplain is able to complete a comprehensive spiritual assessment and initiate appropriate interventions for those needing spiritual support.[2,9,13]

The primary role of the chaplain on a palliative care team is to support and/or accommodate the spiritual and religious needs of patients, families, and staff. Chaplains provide support across cultures and faiths by offering a nonjudgmental presence. Chaplains can be called simply to talk, using religious or nonreligious language, or they can be called to address specific religious needs, such as providing sacraments or other rituals that provide existential comfort. The goal of the chaplain is to aid in restoring identity, meaning, and/or connection to those who invite a chaplain's care. The palliative care chaplain builds on the traditional hospital chaplaincy role by assisting the team in symptom assessment, especially existential distress, eliciting goals of care, advance care planning, and supportive complex decision-making.[14]

Palliative Care Nurse

It is not unusual for a large palliative care team to include both registered nurses (RNs) and advanced practice registered nurses (APRNs). Nurses are educated to focus on the holistic needs of the person, providing supportive care to the physical, psychological, social, and spiritual needs of patients and families, and advocating for their needs. The specialty-trained palliative care nurses build on this nursing foundation by adding expert communication skills, knowledge of pain and symptom assessment and management, expertise in coordination of care, and skill in educating patients, families, and other healthcare professionals about palliative care concepts. Board certification in this nursing specialty is offered through the nursing organization, the Hospice and Palliative Certification Corporation.

Specialty palliative care nurses (PCNs) use expert communication skills,[15] listening to patients and their families and exploring what the patient's values, goals for care, and communication preferences are. The PCN on the team also contributes to pain and symptom assessment and management, is skilled in pharmacological and nonpharmacological approaches to pain and symptoms, and has expertise in equianalgesia. The PCN collaborates with the team to develop a plan to aggressively treat pain and symptoms, to reassess interventions, and to evaluate and report the efficacy to the other healthcare providers involved in the patient's care.

Another key role of the PCN is education for patients and families experiencing serious illness and other healthcare professionals unfamiliar with palliative care.[16] It is often the PCN who initiates and leads debriefing of the staff who have faced challenges in caring for a patient, discussing what went well, what could have been done differently, and lessons learned for the future.

The PCN has a major role in coordinating care among all healthcare providers involved in the patient's care. The nurse collaborates with the IDT to identify which team members should be involved in the patient's care based on the patient's acuity (physical, psychological, social, and/or spiritual needs) and with the patient's other healthcare providers across clinical settings (inpatient, ambulatory care, and hospice) to keep them informed of the plan of care and to ensure that the patient's values and wishes are honored.

Advanced Practice Registered Nurse

Specialty trained and board-certified master's or doctorate-prepared APRNs are valuable members of the palliative care team.[17] As nurses, they are able to fulfill the role described for the specialty PCN; however, they are also licensed providers and can determine and order appropriate diagnostic testing and pharmacologic interventions for patients with serious illness. They receive additional training in communication and advance care planning, and many play a leadership role on the palliative care team. Detailed information on the role of the APRN can be found in Chapter 68 "The Advanced Practice Registered Nurse."

Physician

The palliative care physician brings to the palliative care team the clinical expertise of medical diagnosis, knowledge of the disease course, prognostication, expertise in goals-of-care conversations, and medical management, including pain and symptom management. The American Academy of Hospice and Palliative Medicine recognizes the specialty of palliative medicine and offers board certification for physicians completing a fellowship in Hospice and Palliative Medicine.[18]

In addition to specialty medical management, the palliative care physician is helpful in addressing issues and concerns that the primary team may have, clarifying information, and respecting and advocating for the patient's goals and wishes. The physician can assist the team with discharge planning. Assessing the appropriateness of nursing home placement, a rehabilitation facility, a transitional care facility, or hospice (both home and inpatient hospice care) are part of the scope of practice for the palliative care physician.

Social Worker

Social workers are educated to understand complex family dynamics and are skilled at integrating cultural considerations into care, communicating with patients and families, and advocating for patient preferences.[19] A major aspect of their role in caring for patients with serious illness is to assess the needs, strengths, and resources of the patient and family, build on their strengths, enhance their connections to their resources and supports, and connect them with new resources to meet emotional, legal, and financial needs.[20] While the palliative care social worker (PCSW) will follow the patient and family throughout the illness, various primary social workers may also be involved in other clinic visits or hospitalizations. Clear communication between the other social workers involved and the nurse case managers is crucial to ensure the continuity of care and avoid duplication of effort.[21]

Palliative Care Bereavement Coordinator

The role of bereavement coordinator is not a part of every palliative care program, although bereavement care is part of quality palliative care.[4,9] Bereavement coordinators help to identify and follow-up with families at risk for complicated grief. They send cards and resources to bereaved families and make regular calls to those at risk for or exhibiting signs of complicated grief. Often, they coordinate memorial/celebration of life services for family and staff. Many palliative care teams ask that their social worker or chaplain assist in this role.

Volunteers

Some palliative care programs utilize volunteers to offer additional support and services to patients, the families, and the team, as recommended in Domain 1 of the NCP *Guidelines for Quality Palliative Care*.[9] Volunteers require supplementary palliative care training to meet the unique needs of patients with serious illness and their families.

In order for any volunteer program to thrive, particularly a specialized one, someone must be dedicated to training, guiding, and supporting these volunteers. Volunteer coordinators are an important addition to palliative care teams. Most hospitals have a central volunteer program that recruits, selects, and orients hospital volunteers. A palliative care volunteer coordinator works with this central program to identify volunteers who have the interest and skills that match the needs of patients and families cared for by the team. Furthermore, coordinators provide support to these volunteers who give the gift of their time and presence to patients and families during extremely difficult times.[22] Palliative care volunteers should always have access to the coordinator for debriefing and, if possible, to the chaplain or social worker for loss, grief, and bereavement support and as well as moral distress.[23]

Ancillary Disciplines/Consultants

According to the NCP *Guidelines for Quality Palliative Care*,[9] other disciplines may be included on the patient's team, as needed. These ancillary disciplines are consulted for their expertise in areas of need that have been identified by the palliative care team.

Examples of these therapeutic disciplines include, "child-life specialists, nursing assistants, nutritionists, occupational therapists, recreational therapists, respiratory therapists, pharmacists, physical therapists, massage, art, and music therapists, psychologists, and speech and language pathologists."[9] In addition, complementary and alternative therapies such as acupuncture or Reiki, if available, may be utilized to address pain and symptoms management.[24]

Case Study: Demonstrating the Unique Contributions of IDT Members

Jane Smith, a 40-year-old married woman with two young children was diagnosed with a rapidly progressing neurodegenerative disease, amyotrophic lateral sclerosis (ALS). Jane and her husband, Robert, were both working parents at the time of her diagnosis. She and her family were given the devastating news that her life expectancy was 1–5 years and that her ability to live as she had would change dramatically as her disease progressed. Jane worried how her husband would manage caring for their children, John and Sarah, as well as her elderly mother. Early in her diagnosis, the palliative care team was introduced to Jane and her family. Jane learned that this team would help provide support to her and her family across the disease trajectory, as well as manage any symptoms she developed along the way.

Six months post-diagnosis, Jane developed a pneumonia that resulted in respiratory distress, intubation, and admission to an intensive care unit (ICU). She was weaned from the ventilator after a few weeks and moved to an acute medical unit for further recovery. Unfortunately, her disease began to progress more rapidly, affecting her ability to walk and care for herself independently. Due to the financial burden of her 24/7 care needs, she was transferred to a long-term care unit within the hospital. She remained on this unit another 4 months until her death.

Throughout Jane's hospitalization, the inpatient palliative care team continued to care for her. They provided consistency and care coordination as she changed from one unit to the next. The team was able to assess her changing goals as her illness advanced. Following her intubation in the ICU, Jane stated that she did not wish to go back on a ventilator ever again. She felt very strongly about this decision, even though her husband was hesitant to relinquish this potentially life-prolonging intervention. As her illness advanced, Jane's decisions centered around prolonging her time with her family but stopped short of wanting aggressive resuscitative measures. In this case study, you will see how the palliative care team helped Jane by advocating for her goals of care and framed her decisions with her family and staff in the context of her desired QOL.

The following paragraphs detail how the role of each team member improved patient and family QOL.

Palliative Care Chaplain

The chaplain became acquainted with Jane while participating in morning rounds as a member of the palliative care team. He reviewed her pertinent background information in the medical record and also consulted with the bedside RN to gain insight into the patient's mood, recent medical events, and any observed interactions with family before going to her room.

On first meeting, the chaplain identified himself and inquired whether or not Jane desired a chaplain visit. She welcomed a visit but immediately in the conversation identified herself as "not religious." The chaplain offered affirmation of Jane's experiences with structured religion and invited further broadening of the discussion as to the things that she felt gave her life meaning and connection. Jane stated that she found greatest meaning when she was engaged in her children's lives and, therefore, was experiencing anxiety due to loss of involvement with them because of her current hospitalization. She also stated that she was struggling with loss of autonomy, as she was now dependent on others for her care.

The chaplain employed active listening in an effort to assist the patient in identifying and celebrating ways that her influence continues to play a role in her children's development, exploring ways she could feel less isolated, and allowing emotional space for the patient to safely express her fears and frustrations. At the conclusion of the visit, Jane expressed that she felt less anxious and thanked the chaplain for the opportunity to give voice to her existential struggles. She also indicated that she was open to follow-up visits and invited the chaplain to return when her husband was present so that he could also feel supported. Immediately after the visit, the chaplain documented a detailed spiritual assessment in the patient's medical record and a follow-up plan and consulted with the other members of the palliative care team.

Palliative Care Nurse

The PCN became actively involved in Jane's care during her intensive care unit (ICU) admission. The palliative care nurse completed a thorough physical assessment, paying close attention to Jane's pain and other distressing symptoms. The PCN then gathered information from the ICU team regarding Jane's condition, sharing changes, concerns regarding progression of disease, and treatment options with the rest of the palliative care team. From there, the PCN coordinated a formal family meeting with Jane, her family, and the palliative care team to discuss concerns, changes in condition, and goals of care, and to provide emotional support to Jane and her family. After Jane was successfully extubated, the nurse ensured that all members of the IDT and other healthcare providers were aware that Jane did not want to be re-intubated, documenting the patient's wishes in the electronic medical record.

Knowing that care preferences can change over time, the PCN continued to check in with Jane and her family. The PCN provided a mindful presence to allow Jane and her family to process difficult information and concerns. Although Jane's husband did not agree with her decision not to be re-intubated, the PCN allowed Jane's husband to express his distress and assisted him in reframing expectations for Jane's care through her eyes.

Throughout the trajectory of Jane's hospitalization, the PCN assisted in assessing, planning, intervening, and reassessing Jane's pain and symptoms. Recognizing that Jane's distress was not only physical, but also spiritual and emotional pain, the palliative care nurse collaborated with the chaplain and social workers to ensure that Jane's needs were being addressed. As Jane's disease progressed, she expressed that she did not want to die at home and was aware that it would be too difficult for the family to provide the level of nursing care she needed, 24/7. Although hospice services were offered, she preferred to die in the hospital's long-term care unit, with the palliative care team she knew well.

Palliative Care Physician

The palliative care physician met Jane for the first time at the time of diagnosis, in the neurology clinic and then again as an inpatient when she was admitted to the hospital. In both instances, it was critical to assess her understanding of her disease and its progressive, life-limiting nature; treatment options; and symptoms, as well as her need for psychological, social, and spiritual support.

Management of her dyspnea and pain were critical during her hospitalization. The physician worked with the palliative care team and respiratory therapy to develop a plan to keep Jane as comfortable as possible. Specific conversations with Jane and her husband during her hospital admission included a discussion about the eventual respiratory failure that results from this disease and the treatment options available when that time comes. A discussion of re-intubation and tracheostomy, the risks and benefits, as well as expectations that accompany each option were presented during her hospitalization. QOL and patient values were at the center of these conversations.

During Jane's stay in the long-term care unit, the physician, along with the palliative care team, continued the conversation about goals of care and began to discuss end-of-life planning. That conversation included a discussion of eating for pleasure, despite its aspiration risks. For her, the comfort and pleasure associated with eating was always worth the risk. Jane preferred to die in the long-term care unit rather than at home or in a hospice facility. She requested the palliative care team continue to care for her and her family.

Palliative Care Social Worker

The PCSW, along with the palliative care team physician, met Jane, Robert, and Jane's mother at the neurology clinic shortly after diagnosis to provide emotional support to them for the trauma of Jane's being diagnosed with such a devastating life-limiting illness. The PCSW acknowledged that the grieving of the loss of their life together had already begun and offered support groups locally and online that could help the family, as well as tips on communicating and supporting the children as Jane's disease progressed.

Through the psychosocial assessment, it became clear that the family's support system of friends, neighbors, and faith community had offered to help with whatever was needed, but Jane and Robert were uncomfortable accepting help and were so overwhelmed that they didn't know what help to ask for. The PCSW gave them a free online resource with which to create a care calendar where their needs could be listed and friends could sign up to help; the PCSW helped them identify a neighbor who could manage the website.

When the PCSW met with Jane in the hospital, she was nearing the end of her sick leave from work, which meant the end of her health insurance. The PCSW gave them directions on how to apply for Social Security Disability and took this opportunity to suggest that Jane complete a Healthcare Power of Attorney and a Last Will and Testament.

When Jane was admitted to the ICU with an aspiration event, the PCSW met with Robert and Jane's mother for support, and connected Robert with the Child Life Therapist who guided Robert in how to prepare the children to visit Jane in the ICU and to answer their questions about when Jane would be able to talk to them again. After Jane's continued decline in the transitional care unit left her unable to feed herself, but wanting to eat in spite of risk of aspiration pneumonia, the PCSW had discussions with Robert respecting her wishes, including no re-intubation.

As Jane's death became imminent, the PCSW reconnected Robert with the Child Life therapist for help in telling the children that Jane was dying. Robert was given Grief Recovery books for the children to read after their mother's death and a list of grief resources (counselors, groups, camps, websites, and a book list) for Robert and the children. The chaplain and the PCSW made certain that Jane's room was peaceful and provided support to the family throughout Jane's last day.

The palliative care team, led by the PCSW and chaplain, held a debriefing session for staff the week after her death. They, too, were grieving the loss of this vibrant woman whose independence they grew to admire despite their moral distress that it could hasten her death. Nine months later, at the Hospital's Bereavement Service, which Jane's entire family attended, Robert shared with the PCSW that the bereavement cards he received quarterly from the palliative care team helped him realize that others were still thinking of Jane. He had the children enrolled in a grief camp in the coming months, and the family grief recovery group they attended at their church helped the entire family know they were not alone in their grief.

Volunteers

The Smith family benefited from the presence of palliative care volunteers throughout the course of Jane's hospitalization. When Jane was initially admitted to the ICU, palliative care volunteers provided supportive visits to her family and brought the children coloring books and other activities to use while visiting at the hospital. As Jane improved and was no longer intubated, volunteers were able to communicate with her directly and provide supportive visits when her family members were at school and at work.

The palliative care volunteers continued this supportive relationship as Jane transferred to other units within the hospital. Their continued visitation furnished a consistent, nonclinical relationship based on providing compassionate presence, active listening, and comfort. Over time, the volunteers provided many services to both Jane and her family, including helping her with journaling and assisting her with composing letters and cards for her children after she was gone. As Jane's illness progressed and her family struggled to cope with their inevitable loss, a volunteer assisted with legacy work for her children, making memory stones with Jane's fingerprint. Jane's children were able to carry these stones with her fingerprint in their pockets wherever they went, feeling their mom's presence.

Ancillary Disciplines Consulted

Ethics consultation. After Jane's transfer to a long-term care unit within the hospital, staff grew concerned about her ability to swallow food and drink. Both her family and staff worried she might aspirate again and questioned whether they should continue to provide comfort feeding. Jane made it clear to everyone that eating was an important aspect of her life and she did not want life support if she aspirated. Due to the distress of family and the staff taking care of Jane, an ethics consult was called to help clarify the situation. Through the ethics consultation, it was determined that because her wishes were well-known and documented in her advance directive, there was no conflict with feeding her.

Respiratory therapy. Respiratory therapy was involved throughout Jane's hospitalization from intubation in the ICU to her final hours of life. Respiratory therapists worked with Jane on maintaining her lung function and airway clearance for as long as possible and tailored their interventions to support her wishes of no re-intubation.

Physical and occupational therapy. Physical and occupational therapy were involved in Jane's care plan from her time of diagnosis to help preserve her functional status, safety, and ability to perform activities of daily living (ADLs) independently for as long as possible.

Speech language pathology. Speech language pathologists (SLPs) worked to prolong Jane's ability to speak, eat, and drink by teaching her exercises and compensatory strategies as the disease progressed. Understanding her desire to continue eating and not be re-intubated, they worked to educate Jane, her family, and the staff on foods and techniques to reduce the risk of aspiration events.

Registered dietitian/nutritionist (RDN). As Jane grew weaker, the RDN was consulted for supplemental nutrition via percutaneous endoscopic gastrostomy (PEG) tube. Although Jane did not desire most forms of life support, receiving supplemental nutrition via a PEG tube supported her goal to have as much quality time with her family as possible. The RDN recommended nocturnal feedings with comfort meals during the day. In Jane's final days, the RDN worked with the palliative care team to reassure her husband that supplemental nutrition was no longer necessary and that feedings at this juncture would actually do her harm.

Child life specialists (CLSs). Child life specialists have training in the emotional and developmental needs of children facing illness and expertise in pediatric bereavement and coping strategies. CLSs supported Jane's children during the ICU experience and helped both parents prepare the children for Jane's decline and impending death.

Palliative care bereavement coordinator. The bereavement coordinator followed-up with Jane's family through telephone calls and cards for 12 months following her death. The bereavement coordinator provided resources to help the children, such as bereavement camps and support groups designed for children, as well as resources for Jane's husband. In addition, the bereavement coordinator provided staff debriefings to promote staff grieving and coping. At the yearly remembrance ceremony, Jane's family and staff were reconnected.

Case Study Summary

By having access to a palliative care team that addressed physical, psychological, social, and spiritual needs, and coordinated all necessary services, Jane had the opportunity for the best possible outcomes in the face of her illness. But what made her wishes a potential reality was the communication between her palliative care team and her other healthcare providers. Without assessment, reassessment, and collaboration between disciplines and services, it would not have been possible to tailor her care based upon what was most important to Jane and her family. A strong palliative care team, comprising a physician, nurse, social worker, and chaplain, can support a patient like Jane by honoring her wishes, providing aggressive pain and symptom management, and offering support and grief counseling and spiritual care for existential distress.

Palliative Care Delivery Models

Inpatient Palliative Care Consult Team

Inpatient consult services have grown in number by more than 180%[1] and are now available in 96% of all academic medical centers.[4] Most consult services usually include a basic team of board-certified palliative care physicians and nurses, including advance practice registered nurses. Ideally, a PCSW and chaplain are also on the team, but, in some institutions, the palliative care team must use the institution's social workers and hospital chaplaincy for support. Providers on the palliative care team (physicians and advanced practice registered nurses) are to be compensated for their consulting services, similar to other specialty consult services.[4] Research has demonstrated that inpatient palliative care services decrease hospital costs, ICU admissions, and emergency room visits as well as improve patient satisfaction, alleviate symptom burden, improve hospice utilization, and improve QOL.[1,4,25]

The majority of patients with advanced illness die in acute care settings or in long-term acute care facilities, despite the fact that most people prefer to die at home.[4,10] For patients who are newly diagnosed with a serious illness, the palliative care team assists in providing information regarding the illness trajectory and treatment options and serves as a conduit of communication between the patient and family, healthcare providers, therapy services, and community resources (i.e., home health, Veterans Benefits, ambulatory palliative care, or hospice services). For inpatient consults that arise later in the disease process, the palliative care team often is needed for advance care planning conversations, including hospice care. Patients may not want more diagnostic tests, procedures, or disease-modifying treatments, all of which increase their time spent in observation units or in inpatient settings. It is imperative that the inpatient palliative care team addresses what is most important to the patient so that goals of care are reflective of the patient's values and preferences.

For patients who are actively dying in inpatient settings, a consult to the palliative care team helps identify the patient's goals and preferences for end-of-life care. The palliative care team's role is to not only support and uphold the patient's goals of care, but also to provide support to the family and the primary team. If the inpatient facility has a palliative care unit, transfer to that unit, which has skilled PCNs providing 24/7 care, can provide the best possible care for the patient and family who are unable or uncomfortable returning home with hospice care.

For patients who are discharged from the hospital and wish to continue with life-prolonging treatments, ambulatory palliative care, if available, can assist the patient with pain and symptom management and continue conversations regarding goals of care. Outpatient palliative care usually occurs in ambulatory care centers or specialty clinics.

Ambulatory Palliative Care Teams

The landmark study by Temel et al.[7] demonstrated that outpatient palliative care not only improves QOL for patients with advanced lung cancer, but also improves length of life. Ambulatory palliative care teams have been shown to improve patient and family satisfaction and ensure that care is consistent with patient wishes.[2,8] In addition, this outpatient care improves early access to palliative care, improves symptom management, and has decreased the utilization of hospital resources, especially emergency room visits.[2] During an outpatient palliative care visit, patients can be assessed by many members of the IDT in a single setting and, depending on patient and family need, during one visit.[26]

Community-Based Palliative Care Teams

Although palliative care is predominantly practiced in the inpatient setting, community-based palliative care (CBPC) is rapidly growing and providing services in the place where patients spend most of their time—outside of the hospital.[9,27] CBPC is provided in the patient's home or wherever the patient resides, such as assisted living or skilled nursing facilities. The team's ability to go where the patient is decreases the burden and stress associated with transportation to the ambulatory clinic or physician's office. When the patient is not eligible for hospice care or does not elect hospice services, CBPC fills a gap that had previously existed in the healthcare system.

When palliative care becomes involved earlier in the trajectory of illness and within the patient's home, trusting relationships can be built and difficult conversations regarding goals of care can be done earlier.[28] Research has shown that patients receiving CBPC tend to be referred to hospice earlier and have an increased median and total length of stay on hospice care.[27,28] The team is able to offer support in the home, help establish clear goals of care with the patient and family, and provide expertise in pain and symptom management.[29] This model of palliative care delivery is decreasing unwanted hospital, ICU, and emergency room admissions.[1] However, access to CBPC currently is limited in many areas of the country.

The Hospice Team

Hospice care is palliative care for patients and families in the last 6 months of life who choose to forego disease-modifying treatment.[10] The overall focus of hospice is to provide comfort and improve all domains of QOL: physical, psychological, social, and spiritual. Hospice care is provided by a palliative care IDT including physicians, nurses, social workers, chaplains, hospice aides, volunteers, and other disciplines as needed.

The Medicare Hospice Benefit[11] defines patient's hospice eligibility based on prognostication: when two doctors certify that there is a prognosis equal to or less than 6 months to live, assuming the disease takes its natural course, the patient becomes hospice-eligible.[11] The Medicare hospice benefit, or other insurance hospice benefit, covers the cost for all hospice team services as well as any medical equipment and all medications related to the patient's serious illness at no additional cost. If a patient does not have insurance but is eligible for and desires hospice care, a Medicare-certified hospice must provide care, regardless of ability to pay.[11]

The hospice team delivers care wherever the patient is living, in the home, assisted living, hospital, or long-term care nursing facility. Hospices provide 24/7 coverage as well as short-term general inpatient hospice (GIP) care for patients whose symptoms are difficult to control, as well as short-term respite care for exhausted caregivers caring for the patient in the home.[10] It is important that patients who qualify for hospice-level care and their families are educated about the benefits of hospice care. Many are misinformed, thinking that hospice is a place, rather than a palliative care delivery model, or that hospice care is only for the final days or weeks of life. Early intervention with hospice care provides the best quality care, rather than crisis intervention, for all who are eligible for this care.[30] Additional information about hospice and palliative care is found in Chapter 1.

Building a Palliative Care Team

When considering starting a palliative care team or enhancing a team, many things need to be taken into consideration. It is critical to identify the vision of what the goal of the team is and how it will meet the needs of the institution. This will vary from institution to institution based on resources, mission and size of the institution, administrative priorities, educational requirements, demographics of the patient population, and the plan to include learners, as well as the overall value that palliative care has as an institutional core value. The palliative care members included on the team will vary greatly based on institutional requirements/resources as well as on the team's mission (i.e., whether it is a consult service, an outpatient service, a clinic, or an inpatient unit).[4,5] The leadership within the palliative care team must ensure that all members of the palliative care team share the same vision so that there is no miscommunication about the role which palliative care may fill as it evolves.

Convincing the administration of the importance of palliative care for the institution requires understanding the values that palliative care brings to a healthcare system. The vision/mission of palliative care must coincide with that of the institution. Improved patient and family satisfaction scores as well as substantial cost savings to the institution, including decreased 30-day readmission rates, are data that must be tracked.[31]

Resources for developing a palliative care team are readily available.[4] For the palliative care team to be successful, there must be a business plan that includes exploring the financial impact of the program as well as looking at the basic needs of the evolving program. These needs may include financial support from the institution, a plan to increase the workforce when the program census grows, and monitoring data on the impact of quality improvement, such as improved pain scores or lower readmission numbers.[4] In addition, a plan for recruitment and retention of palliative care clinicians is important to consider at the time of development.

Palliative care teams require leadership and structure so that each member is aware of the defined expectations of his or her role. Much of this work can be accomplished with clear policies and procedures and a strong orientation program. However, the most effective way to build and grow a team is with ongoing, effective team communication.[30] Detailed information on how to start and maintain a strong palliative care team is beyond the purview of this chapter but is available from the Center to Advance Palliative Care.[4]

Sustaining a Healthy, Functioning Palliative Care Team

A healthy team is one in which the members respect and appreciate their team members as individuals and the team as a whole unit. Team members must all share the same team values, mission, and vision. Team members need clearly delineated roles but must understand that there are many aspects of palliative care that are shared by each discipline.[3] There needs to be shared accountability for quality patient and family care, and work and productivity expectations must be transparent.[32]

According to Guideline 1.8 of the NCP *Guidelines for Quality Palliative Care*,[9] the palliative care program must recognize the emotional impact that caring for those with serious illness has on team members. Processes need to be in place to provide support for sustainability. Burnout and compassion fatigue in hospice and palliative care professionals are significant and are on the rise, making retention a problem for some teams. Clinician burnout has been reported to be as high as 62%.[33] Proactive team activities for individual and team self-care, resilience strategies, and healthy work environment are critical to success. Many palliative care teams have adopted personal and team wellness programs; regularly scheduled debriefing sessions to vent frustrations, anger, and concerns; and a plan for crisis debriefing.

Whenever a team comprises more than one individual, conflict is inevitable. It is important that team members are aware of symptoms of stress and conflict and are comfortable discussing them openly. Poorly functioning teams suffer from rivalry, mistrust, and role ambiguity, all of which are toxic to team health. Team building activities that encourage trust and mutual respect will help to prevent these challenges from arising. Most importantly, the team needs to keep its focus on its agreed upon mission and values: care that is in the best interest of the patient and family.[3]

Palliative care requires the expertise of a strong interdisciplinary team to meet the unique and challenging needs of the patients and families that are cared for on a daily basis. Although working as a team adds a layer of challenges, including conflicting work schedules, role overlap, differing opinions, and, on occasion, conflict, team collaboration allows the palliative team to offer a higher level of service for patients and families while supporting the needs of its individual team members.

Conclusion

Palliative care is best delivered by an IDT that attends to the physical, psychological, social, and spiritual well-being of patients with serious illness and their families.

The NCP *Guidelines for Quality Palliative Care* [9]give direction for the structure and processes of developing and sustaining palliative care teams. Interdisciplinary professionals bring their unique individual discipline's expertise to the patient's plan of care and then collaborate as a team to achieve the best possible patient and family outcomes. The models of palliative care delivery vary in their settings, reimbursement, and eligibility; however, the mission and vision for all models of palliative care are focused on the patient and family goals of care and QOL. A team that works collaboratively and addresses individual and team wellness will be resilient and sustainable, despite team challenges and changing dynamics of the healthcare system. Most importantly, the team will be rewarded with the professional satisfaction of delivering quality palliative care to all those in their care.

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CHAPTER 8

Pain Assessment

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Key Points

- Pain is a multidimensional experience.
- There are multiple, persistent barriers to pain assessment.
- Patient's self-report of pain is the gold standard, even for those who are nonverbal or cognitively impaired.
- Patients or residents should be screened for pain on admission to a hospital, clinic, long-term care facility, hospice, or home care setting.
- If pain is reported, a comprehensive pain assessment should be performed at regular intervals, whenever there is a change in the pain, and after any modifications in the pain management plan.
- A comfort/function goal describes how much pain can occur without interfering with function, quality of life, and is the level of pain that will enable function and comfort.
- Dosing analgesics based only on a pain intensity score is not recommended as it disregards the relevance of other vital pain assessment elements (e.g., pain interference on function) and may contribute to untoward patient outcomes.
- Risk factors for and presence of substance use disorders should be assessed in all patients.
- Pain assessment instruments should be evidence-based, valid, and reliable, and culturally tailored based on the patient's age, cognition, and language.
- Healthcare providers need to examine their personal biases and attitudes toward patients with different ethnic backgrounds.
- Patients or residents unable to speak for themselves should be assessed by observation of pain behaviors and family caregiver proxy or surrogate reporting.

Introduction

Unrelieved pain is one of the most frequent reasons for palliative care consultation.[1] Evidence demonstrates that pain is prevalent and undertreated in the palliative care setting, contributing significantly to patient discomfort and suffering at the end of life.[2,3] Among hospitalized patients, multiple distressing symptoms, including pain, worsen during a patient's final admission, and approximately 40% suffer from uncontrolled pain within the last few days of life.[4,5] Even in the care-oriented culture of hospice and palliative care, pain is one of the most bothersome symptoms requiring more intensive management and sedation during the last weeks of life.[6,7] A nationally representative longitudinal survey of US community-dwelling residents found pain to be prevalent in the last year of life, ranging from 54–61%, with a solid upward trend from 1998 through 2010.[8]

Pain is also a concern in patients with cancer throughout the illness trajectory. According to a systematic review/meta-analysis of 122 articles published since 2005, cancer pain prevalence rates are 39% post curative treatment; 55% during anticancer therapy; 66% in advanced, metastatic, or terminal disease; and 51% among all cancer stages.[9] Approximately 40% of cancer patients report moderate to severe pain (defined as ≥5 on a 0–10 numeric rating scale).[9] Regarding pain experience by cancer type, 70% of patients with head and neck cancer experienced the most pain, followed by patients with gynecologic malignancies (60%), those with gastrointestinal (colon, esophageal, pancreatic) cancers (59%), with lung cancer (55%), with breast cancer (54%), and with urogenital (prostate, bladder) cancer (52%).[9]

Pain relief in long-term care (LTC) varies widely, with 45–80% of residents having substantial pain with suboptimal pain treatment.[10] Pain continues to be poorly assessed, with more than one-third of LTC residents having no formal or regularly scheduled pain assessment, despite implementation of pain assessment documentation required by the Minimum Data Set (MDS) 3.0.[11] Even with an intensive educational initiative and support provided to nursing staff in 27 nursing homes, researchers found no statistically significant difference in adherence to clinical guideline practice pain recommendations, with pain continuing to be prevalent in LTC residents.[12]

This chapter reviews various pain types, barriers to pain assessment, and guidelines for pain assessment in the palliative care setting. A multidimensional model for pain assessment is described, and multiple instruments that can be used to assess pain in verbal, nonverbal, and cognitively impaired patients are appraised. Two case studies are presented for discussion.

Pain Types

According to the International Association for the Study of Pain (IASP), pain is defined as "an unpleasant sensory or emotional experience associated with actual or potential tissue damage, or described in terms of such damage. The inability to communicate verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment."[13] Pain has also been clinically defined as "whatever the experiencing person says it is, existing whenever the experiencing person says it does."[14]

Pain is commonly described in terms of categorization along a continuum of duration. An understanding of the characteristics, severity, and nature of the pain is essential to providing appropriate treatment. *Acute pain* is usually of brief duration: hours, days, weeks, or a few months and associated with tissue damage, inflammation, or a surgical procedure. Acute pain serves as a warning that something is wrong and is generally viewed as a time-limited experience. In contrast, *persistent* or *chronic pain* worsens and intensifies with the passage of time, lasts for an extended period (months, years, or a lifetime), and adversely affects the patient's function or well-being. The term "persistent" is favored as it is not associated with the negative stereotype often associated with a chronic pain patient label.[9] Approximately 15% of adults in United States have pain lasting longer than 3 months.[15] Persistent pain may accompany a disease process such as acquired immune deficiency syndrome (AIDS), arthritis or degenerative joint disease, chronic obstructive pulmonary disease (COPD), heart failure, neurological disorders (e.g., multiple sclerosis, cerebrovascular disease, Parkinson's disease), fibromyalgia, sickle cell disease, cystic fibrosis, and diabetes. It may also be associated with an injury that has not resolved within an expected period of time, such as low back pain, trauma, spinal cord injury, complex regional pain syndrome, postherpetic neuralgia, or phantom limb pain. The terms "cancer pain" or "cancer-related pain" have been used to distinguish pain in patients with a malignancy from those without a malignancy (nonmalignant pain). Cancer-related pain can present as acute or persistent pain, related to primary or metastatic disease, the result of treatment (surgery, chemotherapy, biotherapy, radiation therapy, or procedures), side effects of treatment, or infection.[16]

There are two predominant pathophysiologies of pain, nociceptive or neuropathic, although pain can also present with a mixed picture. Nociceptive pain arises from actual or threatened damage to non-neural tissues due to the activation of nociceptors. Nociceptive pain can be further divided into visceral or somatic pain.[13] In contrast, neuropathic pain is caused by injury to the peripheral or central nervous system.[16]

Case Study 1: Pain in a Patient with Rectal Cancer

Mrs. Amelia G. is a 30-year-old Hispanic woman with rectal cancer and lung metastases. She is married, with two children, ages 3 and 7 years. Her husband is rarely at home due to traveling with his job. Her mother lives with her to help care for the children. Three years ago, after delivering her baby, she developed bleeding from hemorrhoids. Subsequently, she began to have abdominal pain and marked constipation accompanied by an approximate 50-pound weight loss. She had insurance issues and was unable to see a primary care physician for 6 months. Physical exam revealed an anorectal mass and colonoscopy showed a large, obstructing, fungating mass in the rectum. No metastatic disease was present on computed tomography (CT) chest, abdomen, and pelvis. She underwent a resection and diverting colostomy; biopsies showed well to moderately differentiated invasive adenocarcinoma. Positron emission tomography (PET) and CT scan suggested increased metabolic activity in lymph nodes adjacent to the rectal mass and left perihilar region and a right lower lung nodule consistent with metastatic disease. She underwent video-assisted thoracoscopic surgery (VATS); the right lung nodule was positive for metastatic disease. Approximately 4 weeks postoperative, she started chemotherapy with the FOLFOX regimen (5 FU, leucovorin, oxaliplatin) every 14 days. Bevacizumab (Avastin) and Neupogen were added with the third cycle. PET/CT after 2 months of chemotherapy showed no evidence of active disease. She completed her chemotherapy concurrently with radiation therapy. A restaging PET scan showed no progressive disease. She was then scheduled for a low anterior resection and possible ostomy reversal, which revealed residual rectal adenocarcinoma, minimal treatment effect, and perineural invasion. She continued with chemotherapy, and 6 months later a CT scan showed enlarging pulmonary nodules consistent with disseminated cancer recurrence in her lungs. She also developed left hip pain and was found to have a sacral fracture. A month later, a PET/CT showed more extensive bilateral pulmonary metastatic disease with mediastinal and hilar adenopathy. She was recommended to start a different chemotherapy regimen, but delayed initiation of chemotherapy for a number of months to get stronger. She received FOLFIRI chemotherapy at reduced doses with a plan to add panitumumab when she tolerates the current treatment.

Her symptoms included anorexia, fatigue, neuropathy in her feet related to prior oxaliplatin, cough with occasional hemoptysis, anxiety, intermittent diarrhea, and persistent and breakthrough pain in her abdomen and back. She took oxycodone 10 mg every 3 to 4 hours as needed for pain and alprazolam for anxiety. She was evaluated and counseled by her dietician. She verbalized understanding that her cancer is "serious," but remained hopeful to live as long as she can so she can care for her children. After much encouragement, she agreed to a palliative care referral for symptom management and to provide support for her family.

Discussion Questions

1. What are the types of pain that Amelia experienced?
2. What are appropriate ways of assessing her pain?
3. Based on the patient's condition and pain experience, what pharmacological approaches might you suggest for pain control? What, if any, adjuvants might be helpful to include? What long-acting opioid might you suggest?
4. What nonpharmacological strategies would you incorporate into the pain management plan of care?
5. What other symptoms or side effects might you be concerned about? How will you address these? In particular, how would you manage opioid-induced constipation?
6. How does the patient's prognosis affect the intensity of her pain?
7. Describe how the patient's ethnicity may affect her expression of pain, her response to analgesics, and the provider's management of her pain?

Barriers to Optimal Pain Assessment

Over the past five decades, a plethora of research has generated knowledge about pain and its management. However, problems continue in the misuse of information or unwillingness of healthcare professionals to appropriately apply knowledge from research and advances in technology. Furthermore, clinicians fail to adequately evaluate or assess the nature of pain or the totality of a patient's problems. The current opioid crisis has also introduced new barriers to the adequate and timely control of pain in patients with chronic conditions, as well as in those in palliative care settings. Review Box 8.1 for multiple barriers to optimal pain assessment.[17–21]

Box 8.1 Barriers to Optimal Pain Assessment

Healthcare Professional Barriers

Lack of identification of pain assessment and relief as a priority in patient care

Inadequate knowledge about pain assessment

Perceived lack of time to conduct and document a pain assessment and reassessment

Failure to use valid and reliable pain measurement instruments

Inability of clinician to empathize or establish rapport with patient

Fear of patient or family caregiver opioid misuse

Lack of care continuity

Lack of communication among the healthcare professional team

Prejudice or bias in dealing with patients

Failure to accept the patient's pain reports

Healthcare System Barriers

A system that fails to hold healthcare professionals accountable for pain assessment

Shorter lengths of stay, early discharge without adequate time to assess pain and evaluate newly prescribed pain management regimens

Lack of criteria or availability of culturally tailored instruments for pain assessment in certain settings

Lack of institutional policies for performance and documentation of pain assessment by electronic health record

Lack of time to talk with patients about pain

Lack of access to a pain management specialist

Restrictive opioid prescription policies

Patient, Family, Societal Barriers

The highly subjective and personal nature of the pain experience

Lack of patient communication with healthcare professionals about pain:

- Lack of a common language to describe pain
- Compromised communication skills, such as sensory or cognitive impairment
- Patient fears or beliefs (addiction, not being believed, not wanting to bother staff, age-related stoicism, doesn't report pain because "nothing helps," curative therapy may be curtailed due to pain)
- Patient inability to pay for medications or self-care strategies
- Marginal patient involvement in pain plan of care
- Negative public image of opioids

Source: Adapted from References 17–21.

Pain Assessment Guidelines and Standards

Recognition of the widespread inadequacy of pain assessment and management has prompted corrective efforts within many healthcare disciplines, including nursing, medicine, pharmacy, and pain management organizations to develop clinical practice guidelines and quality assurance recommendations for the assessment and management of acute, cancer, and end-of-life pain.[10,16,21–30] In addition, the Centers for Disease Control (CDC) Guideline for Prescribing Opioids for Chronic Pain[15] focuses on three main areas: (1) determining when to initiate or continue opioids in patients with chronic pain, (2) opioid selection, and (3) assessing risk and addressing harms of opioid use in all patients. Although the guidelines are not aimed at cancer patients receiving active treatment and patients receiving palliative or end-of-life care, they have the potential to influence pain assessment and use of opioids in these populations and settings.

Despite the availability of effective medications and clinical guidelines for pain management, pain control is suboptimal in a sizeable proportion of patients with cancer pain. The National Comprehensive Cancer Network Guidelines for Cancer Pain recommend a comprehensive and multimodal pain management approach.[16] Changes in standards and pain management guidelines are continually evolving as more data are discovered about the effectiveness of assessment tools in relationship to prescribing patterns of analgesics. For example, the American Society of Pain Management Nurses (ASPMN)[31] published a position paper on not prescribing and dosing opioid analgesics based solely on a patient's pain intensity as it disregards the relevance of other vital elements of an assessment and may contribute to untoward patient outcomes. Additionally, the Joint Commission[32] has announced new pain assessment and management standards that include the following:

- Identifying a leadership team responsible for safe opioid pain management
- Involving patients in their treatment plan, setting realistic goals and expectations
- Promoting safe opioid use by identifying and monitoring high-risk patients
- Facilitating clinician access to prescription drug-monitoring databases
- Conducting performance improvement activities focusing on pain assessment and management to increase quality and safety for patients

In particular, each accredited hospital must have defined criteria to screen, assess, and reassess pain consistent with the patient's age, condition, and ability to understand. This underscores the need for culturally sensitive, age-appropriate pain rating scale availability to assist with assessment activities.

Patient-centered care requires that healthcare professionals seek opportunities to empower patients and family caregivers in decision-making about their care, taking into account their personal preferences and values. It also includes evaluation of the patient's knowledge, beliefs, concerns, and misconceptions about pain and its management.[33,34] Table 8.1 reviews various barriers that may play a role in pain assessment, function, and response to treatment.[33,34] Patients may be reluctant to tell the nurse and other healthcare providers when they have pain. They may attempt to

Table 8.1 Patient and family caregiver beliefs, concerns, and misconceptions about pain and its management

Disease-related	◆ If the pain is worse, it must mean I am getting worse or my cancer is spreading. ◆ Pain is inevitable. I just need to bear it. ◆ If I tell about my pain it may lead to more tests and treatments.
Sociocultural or spiritual-related	◆ Admitting pain is a sign of weakness. ◆ I don't want to worry my family. ◆ If I talk about my pain it may lead to a loss of independence. ◆ Good patients avoid talking about pain. ◆ It's OK to suffer; that's part of life and a way to eternal life. ◆ I don't want to bother the nurse or doctor; they're busy with other patients.
Medication-related	◆ I better wait to take my pain medication until I really need it or else it won't work later. ◆ My family thinks the pain medication makes me "spacey"; I'd better hold back. ◆ If it's morphine, I must be getting close to the end. ◆ If I take opioids regularly, I will get addicted. ◆ If I take my pain medication before I hurt, I will end up taking too much. It's better to "hang in there and tough it out." ◆ I'd rather have a good bowel movement than take pain medication and get constipated. ◆ If I take too much pain medication, I could die.
Family caregiver beliefs, concerns, misconceptions	◆ My loved one will experience too many side effects ('knocked out', drowsy, or constipated). ◆ Pain treatments may not work. ◆ I worry about overdose. ◆ I am concerned about tolerance. ◆ I am concerned about my loved one becoming addicted. ◆ My loved one does not want to be viewed as weak.

Source: Adapted from References 33, 34.

minimize its severity, may not know they can expect pain relief, and may be concerned about taking pain medications for fear of deleterious effects. Involving patients and family caregivers in the pain assessment process is integral to improving pain management with the desired outcome of decreased pain for patients.

Pain Assessment

Accurate pain assessment is the cornerstone to optimal pain management; it is a continuous process that encompasses multidimensional factors. In formulating a pain management plan of care, a comprehensive pain assessment is crucial and includes a detailed history, a comprehensive physical examination, and patient self-report of pain.

History

It is important to take a detailed history incorporating a review of events leading up to the present illness, key medical comorbidities (including medication use), symptoms, substance abuse disorder (including aberrancy and medication diversion), genetics, and psychological and sociocultural issues that may contribute to pain and/or impact pain management and response to treatment. In the future, genetics could play a significant role in pain assessment and treatment. Research findings have now substantiated the role of pharmacogenomics in affecting individual variability in drug responses.[35] Pharmacogenomics is the study of the effects of genetic factors or genome on drug responses. Soon, healthcare providers may be able to predict an individual's response to particular analgesics based upon pharmacogenetic test results. Increased availability and decreased costs may lead to greater provider utilization of pharmacogenetic testing to determine the best drug to prescribe for an individual patient with various conditions.

Physical Examination

A comprehensive physical examination includes inspection of affected painful areas and common referred pain locations and evaluation of musculoskeletal and neurological systems, especially if neuropathic pain is suspected. In frail or terminally ill patients, physical examination maneuvers and diagnostic tests should be performed only if the findings will potentially change or facilitate the treatment plan. As pain is often accompanied with depression in more than one-third of patients, a psychological exam or psychosocial assessment may be warranted.[36] The burden and potential discomfort of any diagnostic test must be weighed against the potential benefit of the information obtained.

Patient Self-Report

A patient's self-report of pain is most valuable in directing pain management. Pain mnemonics (displayed in Table 8.2) can assist nurses and other healthcare providers in querying patients about key pain assessment components.[37–40] The WILDA approach begins with an open-ended question, "Tell me about your pain," facilitating the patient's story and including the most problematic aspects of the pain experience.[40]

- ***Words***: Ask the patient to describe his pain or discomfort using descriptors. Table 8.3 summarizes pain types, etiological factors, descriptors, and potential interventions based on pain type.[41]

Table 8.2 Pain mnemonics

Mnemonic	Assessment parameters
OLDCART	◆ **O**nset: When did the pain start? ◆ **L**ocation: Where is the pain located? ◆ **D**uration: How often does the pain occur? How long does the pain last? ◆ **C**haracteristics: How does the pain feel (intensity)? What words would you use to describe the pain? ◆ **A**ggravating Factors: What makes your pain worse? ◆ **R**elieving Factors: What makes your pain better? ◆ **T**reatment: What treatments have you tried to control the pain? How are they working? How do the treatments affect the pain intensity?
PEG	◆ **P**ain on average ◆ **E**njoyment: Interference with enjoyment of life ◆ **G**eneral activity: Interference with general activity
PQRST(A)	◆ **P**rovocation/Palliation: What caused it? What relieves it? ◆ **Q**uality: What does it feel like? ◆ **R**egion/**R**adiation: Where is the pain located? Does the pain radiate? ◆ **S**everity: How severe is the pain on a 0 to 10 scale? ◆ **T**iming: Constant or intermittent? ◆ **A**djuvants : What has made it better? What makes the pain worse?
WILDA	◆ **W**ords used to describe the pain ◆ **I**ntensity: On a scale of 0–10, what is your pain now, at rest, with movement, worst pain possible in the past 24 hours? What is your comfort/function goal? ◆ **L**ocation: Where is your pain? ◆ **D**uration: Is the pain constant? Does the pain come and go? Do you have both types of pain (one that is constant and one that comes and goes)? ◆ **A**ggravating/**A**lleviating factors: What makes the pain worse? What makes the pain better?

Source: Adapted from References 37–40.

Screening tools are available to enhance and refine neuropathic pain assessment and management.[42–44] For example, the 11-item neuropathic pain scale quantifies neuropathic pain severity and response to treatment.[45]

- ***Intensity***: Using the 0–10 numeric rating scale (0 = no pain and 10 = worst pain possible), ask the patient:
  - What is your pain now, at rest, with movement, and after a pain-relieving intervention?
  - In the past 24 hours, what was your least, worst, average pain?
  - What is your comfort/function goal?
- Three levels of pain intensity are mild (1–3), moderate (4–6), and severe (7–10).[16] The comfort/function goal describes how much pain can occur without interfering with function or quality of life and is the level of pain that will enable function and comfort. Pain intensity can also be quantitatively measured with a verbal descriptor scale, faces scale, or pain thermometer (scales are discussed later in this chapter). The nurse must consider the practicality, ease, and acceptability of the instrument's use by the palliative care patient. While an assessment of intensity captures only one aspect of the pain experience, it is the most frequently used parameter in clinical practice.
- ***Location***: Ask the patient, "Where is your pain? Do you have pain in more than one area?" Encourage the patient to point or place a finger on the area involved. The majority of cancer patients have pain in two or more sites[16]; therefore, it is crucial to ask questions about pain location. Separate pain histories should be acquired for each major pain complaint because their causes may differ and the treatment plan must be tailored to the particular pain type. For example, neuropathic pain may radiate and follow a dermatomal path; pain that is deep in the abdomen may be visceral; and when a patient points to an area that is well-localized and nonradiating, the pain may be somatic, possibly indicating bone metastasis.
- ***Duration***: Ask the patient, "Is your pain always there (persistent)? Does it come and go (intermittent)? Or do you have both types of pain?" Patients may experience "breakthrough" pain (BTP), an intermittent, transitory flare of pain, with several subtypes described—incidental, spontaneous, or end-of-dose failure pain.[46] Patients with progressive diseases such as cancer and AIDS can experience persistent pain that has an ill-defined onset and unknown duration. Asking about pain duration can determine if controlled-release and/or immediate-release opioids are appropriate.
- ***Aggravating and Alleviating Factors***: Ask the patient, "What makes the pain worse or better?" Pain interference with functional status can be measured by determining the pain's effects on activity, function (walking or repositioning in bed), energy, falling and/or staying asleep, relationships, mood, and/or appetite. Pain interference with functional status is highly correlated with pain intensity scores; a pain intensity score of 4 or higher has been shown to significantly interfere with daily

Table 8.3 Pain descriptors

Pain type	Etiological factors	Descriptors	Potential interventions
Neuropathic	Peripheral or central nervous system injury ◆ Nerve involvement by tumor ◆ Spinal cord compression ◆ Neuralgia (trigeminal, post herpetic) ◆ Peripheral neuropathies (microtubule inhibitors, viral or antiretroviral therapies, diabetes) ◆ Post stroke pain ◆ Phantom pain ◆ Radiation plexopathy	Burning Electrical Numb "Pins and needles" Radiating Shooting Tingling	Anticonvulsants Antidepressants Local anesthetics Corticosteroids Nerve blocks ±opioids (e.g., tramadol, methadone)
Somatic	Nociceptor activation or injury to superficial cutaneous and deep musculoskeletal structures ◆ Bone or spine metastasis ◆ Fractures ◆ Arthritis ◆ Osteoporosis ◆ Immobility	Aching Dull Sore Throbbing	Nonsteroidal anti-inflammatory drugs (NSAIDs) Corticosteroids Muscle relaxants Bisphosphonates Radiation therapy (bone metastasis) ±opioids
Visceral	◆ Bowel obstruction ◆ Venous occlusion or ischemia ◆ Liver metastasis ◆ Ascites ◆ Post abdominal or thoracic surgery ◆ Pancreatitis ◆ Cancers in the abdomen and chest	Bloated Crampy Deep Pressure Squeezing Stretching	NSAIDs Opioids (use with caution in patients with bowel obstruction) Spinal analgesia
Psychological	Psychological disorders	Hurts everywhere	Psychiatric treatment, support, nonpharmacologic strategies

Source: Adapted from Reference 41.

functioning.[47] Analgesics or nonpharmacologic interventions should be administered at least an hour before activity to decrease discomfort.

Ongoing and subsequent evaluations are necessary to determine the effectiveness of pain relief measures and to identify any new pain. Patients should be asked whether they have pain (screened for pain) on admission to a hospital, clinic, long-term care facility, hospice, or home care agency. If pain or discomfort is reported, a comprehensive pain assessment should be performed at regular intervals, whenever there is a change in the pain, and after any pain management plan modifications. Reassessment of pain intensity should occur after each pain management intervention, once sufficient time has elapsed for the treatment to reach peak effect (e.g., 15–30 minutes after a parenteral medication and within 1 hour of administration of oral medication or other nonpharmacologic intervention).[16] Pain assessment and reassessment should be individualized and documented so that interdisciplinary team members have an understanding of the pain problem. Information about the patient's pain can be obtained from multiple sources: verbal self-report, observations, interviews with the patient and family caregiver, review of healthcare data, and feedback from other healthcare providers.

Pain is uniquely personal and subjective. The quality and usefulness of any assessment is only as good as the ability of the assessor to be thoroughly patient-focused. This means listening empathetically, maintaining open communication, and validating or legitimizing the concerns of the patient and family caregivers. A clinician's understanding of the patient's pain and accompanying symptoms confirms that there is genuine personal interest in facilitating a positive pain management outcome.

Finally, pain does not occur in isolation. Other symptoms and concerns experienced by the patient compound the suffering associated with pain. *Total pain* has been described as the sum of the following interactions: physical, psychological, social, and spiritual.[48] At times, patients describe their whole life as painful. The provision of palliative care to relieve pain and suffering is based on the conceptual model of the whole person experiencing "total pain."

Case Study 2: Pain in a Patient with COPD

Mr. Joe M is a 72-year-old man with a 7-year history of COPD related to cigarette smoking, construction work, and asbestos remediation. He began smoking at a very young age and developed a 2-pack per day habit. At the age of 58, he was finally able to quit smoking but had decreased pulmonary function with symptoms of chronic cough, sputum, and shortness of breath on exertion such as walking on a steep incline or stairs. Other secondary diagnoses include coronary artery disease, stable angina, osteoporosis with mild kyphosis of the upper spine, diabetes mellitus controlled with oral medication, and gastroesophageal reflux disease (GERD). He was previously diagnosed with anxiety and depression and moderately consumed alcohol. He has slowly and steadily declined and has had difficulties performing activities of daily living. He was not able to do the things he enjoys and just does "some things around the house."

Last week, just prior to attending church, he had persistent coughing and developed sudden severe shortness of breath and left-sided chest pain. His family thought he might be having a heart attack and took him to the local hospital's Emergency Department. He was found to have a spontaneous pneumothorax. A chest tube was placed emergently, which expanded his lung. However, he had a persistent air leak and developed a hospital-acquired pneumonia. After 1 week, he was finally able to have the chest tube removed. Two days later, he went home, on oxygen therapy (2 L, nasal prongs). Once home, he began questioning the worth of continued treatment and asked his wife, "Would it be a sin to stop?"

Mr. M was referred to your palliative care clinic because of difficult to manage pain, dyspnea, depression, anxiety, and a significant loss of functional status after this recent hospitalization. He was discharged from the hospital with hydrocodone 5 mg/APAP 325 mg PRN for "post-procedural pain" and told that he should not need this for more than a few days to a week. His primary care physician was aware of the recently released CDC opioid guidelines for chronic pain, which has made him uncomfortable prescribing opioids for Mr. M. His physician was hopeful that an adjuvant medication may work for his pain and agreed to a trial of a long-acting opioid only if the patient and family were amenable and the palliative care interdisciplinary team agreed to do the prescribing and monitoring.

Mr. M said, "I can't seem to 'bounce back.'" His wife Kay and daughter Abby accompanied him to the palliative care clinic appointment. They expressed concern about this referral, thinking palliative care means hospice, but decided to come since they are worried about his increasing pain. They were also anxious about him becoming addicted to pain medication. Pain limited his activity and plans for home physical therapy. His pain was a 6/10 in his chest and back.

Mr. M, a stoic man, had been relatively active in his Roman Catholic congregation, although lately he did not attend Mass due to pain and fatigue. He never wanted to be a "bother" to his family. He continued to question ongoing treatment and was afraid to raise this issue with his priest or church friends out of fear that he would not be supported in his wishes.

Discussion Questions

1. Based on what you have learned about Mr. M's condition, comorbidities, and complications of COPD, what type(s) of pain might he be experiencing?
2. How would you assess Mr. M's pain? What instruments might be helpful in understanding his pain experience?
3. What potential barriers exist that may impact his ability to receive optimal pain management? How would you address these with Mr. M and his family?
4. Based on Mr. M's condition and pain experience, what pharmacological approaches might you suggest for pain control? What, if any, adjuvants might be helpful to include? What long-acting opioid might you suggest?
5. What nonpharmacological strategies would you incorporate into the pain management plan of care?
6. What other symptoms or side effects might you be concerned about? How will you address these? In particular, how would you manage opioid-induced constipation?

Three months later, Mr. M decided to forego additional therapy and enrolled in hospice. His pain was well managed at home. Over the last week of his life, he became unresponsive yet he still seemed to have pain and discomfort.

Discussion Questions

7. What pain assessment instruments can be used to assess his pain?
8. How would you incorporate his family caregivers in the assessment process?

Multidimensional Model for Pain Assessment

An individual's pain is unique; it is actualized by the multidimensionality of the experience and the interaction among factors both within the individual and in interaction with others.[49–53] Pain is determined by the interaction of three components: the sensory/discriminative (selection and modulation of pain sensations), the motivational/affective (affective reactions to pain via the brain's reticular formation and limbic system), and the cognitive (past or present experiences of pain).[49] Evidence supports the usefulness of a multidimensional model for pain by describing theoretical components of the pain experience: physiologic, sensory, affective, cognitive, behavioral, and sociocultural.[50,51] The sociocultural dimension, comprising a broad range of ethnocultural, social, demographic, and spiritual/religious factors, influences an individual's perception of and responses to pain and its management. Environmental conditions or stimuli such as excessive noise, lighting, or extreme temperatures may be sources of stress for individuals in pain and may negatively affect the pain experience.[53] Creating a peaceful environment may assist in alleviating the patient's pain.

The multidimensional approach to pain assessment provides the foundation to improve palliative care outcomes and to positively impact a patient's quality of life. Questions guiding a multidimensional pain assessment are reviewed in Table 8.4. We will further examine the various components of the sociocultural dimension.

Sociocultural Dimension

The sociocultural dimension encompasses all of the demographic variables (e.g., age, gender, ethnicity, spirituality, marital status, social support) of the patient experiencing pain. Although many studies have examined these factors in regards to pain assessment, treatment, and outcomes, few have concentrated on their highly interactive nature. Ultimately, all of these factors can influence pain assessment.

Age

Much of the pain literature has called attention to the problem of inadequate pain assessment and management in the elderly in a palliative care setting. Elderly patients suffer disproportionately from chronic painful conditions and have multiple diagnoses with complex problems and accompanying pain. Elders have physical, psychological, and social needs distinct from those of younger and middle-aged adults.

Pain assessment may be more problematic in elderly patients because their reporting of pain may differ from that of younger patients due to their increased stoicism. Elderly people often present with failures in memory, depression, and sensory impairments that may

Table 8.4 Multidimensional pain assessment

Dimension	Question
Physiological/Sensory	What is the cause of the patient's pain? How does the patient describe pain?
Psychological/Affective	How does the patient's emotional state affect report of pain? How does the pain influence the patient's mood or affect?
Cognitive	How do patient's/family caregiver's knowledge, attitudes, and beliefs affect the pain experience? What is the meaning of pain to the patient/family caregiver? What is the patient's past experience with pain and its management and how does this impact the pain experience?
Behavioral	How can you tell the patient is experiencing pain? What pain behaviors or nonverbal cues inform you that the patient may be experiencing pain? What strategies have the patient/family caregiver tried to decrease pain?
Sociocultural	What social support systems does the patient have in place to assist in the pain management care plan? How does the patient's cultural background affect the pain experience, expression, coping, and management? How does the patient's spirituality/religion affect the pain experience, expression, coping, and management?
Environmental	How does the environment affect patient's pain expression or experience?

hinder history-taking. They may also underreport pain because they believe pain is a part of aging. Moreover, dependent elderly people may not report pain because they do not want to bother the nurse or doctor and are concerned that they will cause more distress in their family caregivers.[34] It is important to pay particular attention to pain assessment in the elderly so that the chance of inadequate analgesia is decreased. Dementia, cognitive and sensory impairments, and disabilities can make pain assessment and management more difficult and will be discussed later in this chapter. Loss of hearing and visual acuity may impede communication, as well as dementia and memory loss. Despite these challenges, clinicians should recognize that self-assessment pain scales can often be used reliably in older patients with mild to moderate dementia and even in some with severe dementia. Behavioral scales can detect possible pain and should only be used in patients who cannot complete a self-report.

Gender

Gender differences may affect sensitivity to pain, tolerance, distress, willingness to report pain, exaggeration of pain, and nonverbal expression. Research has demonstrated that men show more stoicism than women, women exhibit lower pain thresholds and less tolerance to noxious stimuli than men, women become more upset when pain prevents them from doing things they enjoy, women seek care of pain sooner, and responses to analgesics and pain prevalence in various conditions may vary according to gender.[54,55] It is important to note that gender differences in pain response for patients with chronic pain are not universal and do not exert a large effect.[56] Explanations that require further investigation include molecular and genetic mechanisms, hormonal influences, and sociocultural and psychological effects. Nurses and other healthcare professionals need to be mindful of possible gender differences when assessing pain and planning individualized care for persons in pain. However, until there are more definitive data, men and women should receive similar pain care based upon individualized assessments.

Ethnicity

Significant racial and ethnic disparities exist throughout healthcare settings suggesting both inequitable treatment and disparate pain care outcomes.[57] To avoid disparities in pain treatment, providers must assess the effects of ethnicity on pain expression and perception. The term "ethnicity" refers to differences among groups of people according to their common language, traditions, shared origins, social backgrounds, culture, and physical characteristics. Bates's biocultural model proposed that culturally accepted patterns of ethnic meanings of pain may influence the neurophysiological processing of nociceptive information that is responsible for pain threshold, pain tolerance, pain behavior, and expression.[52] Research studies have documented that ethnic differences in pain perception exist in a variety of clinical pain conditions, and neurobiological factors may contribute to these differences.[58]

Ethnic minorities are not appropriately assessed for pain and are at risk for undertreatment.[58–61] Pain has been underestimated in Latinos and African Americans and has been associated with inadequate pain management.[58–61] Differences in cultural backgrounds among patient and healthcare providers may result in false beliefs, misinterpretations, lack of trust, and decreased communication about pain.[61] Minority patients, in particular those who speak English as a second language, may be at increased risk due to lack of clear communication and other biases. While pain assessment instruments are accessible in various languages, the translations may not capture cultural nuances or meanings.[60] When caring for a person experiencing pain, the healthcare provider must avoid cultural stereotyping and provide culturally sensitive assessment and educational materials, enlisting the support of an interpreter or navigator who speaks the patient's language when needed.[61] A crucial element of any initiative on pain must focus on improving pain care for racial and ethnic minorities, the poor, and other vulnerable populations.[57]

Marital Status and Social Support

While there is scant literature related to the influence of marital status, family, and social support on the patient's pain experience, it is important to understand and assess the type of support patients receive from family caregivers as it may influence pain expression, meaning, and the ability to comply with therapeutic recommendations.

Spirituality

The spiritual dimension may influence a person's pain response, expression, and experience. Whereas pain refers to a physical sensation, suffering refers to the quest for meaning, purpose, and fulfillment. Unrelieved physical pain may cause emotional or spiritual suffering, yet suffering may occur in the absence of pain. Many patients believe that pain and suffering are meaningful signs of the presence of a higher being and must be endured; others are outraged by the pain and suffering they must endure and demand alleviation. Healthcare providers should give patients the chance to verbalize their personal points of view. Assessing a patient's existential view of pain, suffering, and spiritual pain is important as it may impact healing and dying processes. Suggestions for clinical implications include nurses' and providers' examination of their own spirituality and how that could affect their communication with patients, exploring respectful communication with patients about spirituality and its effects on pain, inclusion of spirituality in education and support programs for both patients and healthcare providers, incorporation of spiritual preferences in comfort strategies where appropriate, and referral to spiritual care providers.

Financial Status

When assessing pain, it is also important to consider the patient's financial status. Insurance companies may require a patient to take a tiered approach to pain medications, require the use of certain opioids over others, or set quantity limits on the amount of medication allowed in a given time frame. Regardless of how thorough pain assessment is, treatment will not be effective if patients cannot obtain the medication. It is essential that providers and nurses be aware of the changing landscape and provide sufficient support for patients.

Past Experiences

Patients should be asked about their prior experiences with pain. For example, many patients have listed allergies to medications that are actually potential side effects, such as "nausea" or "constipation." These are predictable, nonallergic reactions based on the properties of the drugs. Assessing which medications a patient has tried before and his or her response or perceived response to those treatments can help to guide recommendations for treatment.

Substance Abuse

The increased focus on opioid abuse and the opioid crisis in the United States adds an additional challenge or layer to the assessment of a patient's pain. Patients with a history of addiction are another high-risk population for undertreatment of pain and for misuse of opioid analgesics. Providers may be opiophobic, may lack trust, and may have inadequate knowledge about addiction and how to manage pain in those with a history of or current substance use; all interfere with optimal management.[62] Caring for palliative care patients with active substance abuse is difficult as providers attempt to manage pain without contributing to addiction.

In addition to conducting a pain assessment as previously described, providers must assess for addiction risk by using one of many opioid-specific screening tools (e.g., Opioid Risk Tool, SOAPP-R).[63] These instruments provide scoring for risk stratification based on multiple factors (age, gender, personal or family history of substance abuse, history of psychiatric illness or preadolescent sexual abuse). The Opioid-Related Behaviours in Treatment (ORBIT) scale, designed to be brief (10-items), identifies behaviors indicative of problems relating to opioid therapy such as nonadherence, diversion, and hazardous use or misuse. It also facilitates measurement of change over time; however, additional validation of the tool is required.[64]

Relevant outcomes of opioid therapy in patients with a history of addiction should include assessment of the five A's (analgesia, activities of daily living, adverse events, aberrant activities, and adjuvant use) prior to opioid initiation and regularly throughout a treatment course (refer to Table 8.5).[62,65] Ongoing communication

Table 8.5 The 5 A's

5 A's goals	Definition	Assessment
Analgesia	Level of comfort	◆ Decrease in pain intensity ◆ Effectiveness of the intervention on the pain
Activities of daily living and affect	Functional status	◆ Increased physical activity ◆ Ability to cope with illness and symptoms ◆ Improved psychological affect ◆ Family/social relationships intact ◆ Appropriate medication and healthcare utilization
Adverse events or effects	Side effects related to treatment	◆ Constipation ◆ Mental status or cognitive changes • Sedation • Euphoria • Confusion ◆ Respiratory depression ◆ Other physical and psychological effects
Aberrant activities	Behaviors that warn of potential substance misuse, abuse, or addiction	◆ Behaviors that suggest concern, e.g., loss of medications, early requests for prescriptions, lack of approval for dose escalation, concurrent illicit drug use, using an unsanctioned route of administration, and repeated resistance to the recommended treatment plan
Adjuvants	Adjuvant medication use	◆ Use of adjuvants should be maximized and titrated upward to decrease opioid requirements ◆ Include nonpharmacologic interventions

Source: Adapted from References 62, 65.

and assessment are keys to maintaining comfort while preventing misuse, abuse, and diversion. For additional information about managing pain in patients with substance use disorder, please refer to Chapter 42 for greater detail.

Pain Intensity Assessment Scales

Pain is a subjective, self-reported experience; the ability to quantify the intensity of pain is essential to monitoring a patient's responsiveness to analgesia. The most commonly used pain intensity scales, the numeric rating scale (NRS), verbal descriptor scale (VDS), Wong–Baker FACES pain scale, Faces Pain Scale-Revised (FPS-R), vertical pain thermometer, and visual analogue scale (VAS), are illustrated in Figure 8.1[66,67] and reviewed in Table 8.6.[67–74] These are effective, reproducible means of measuring pain, can be universally implemented, and are regularly applied in palliative care settings.

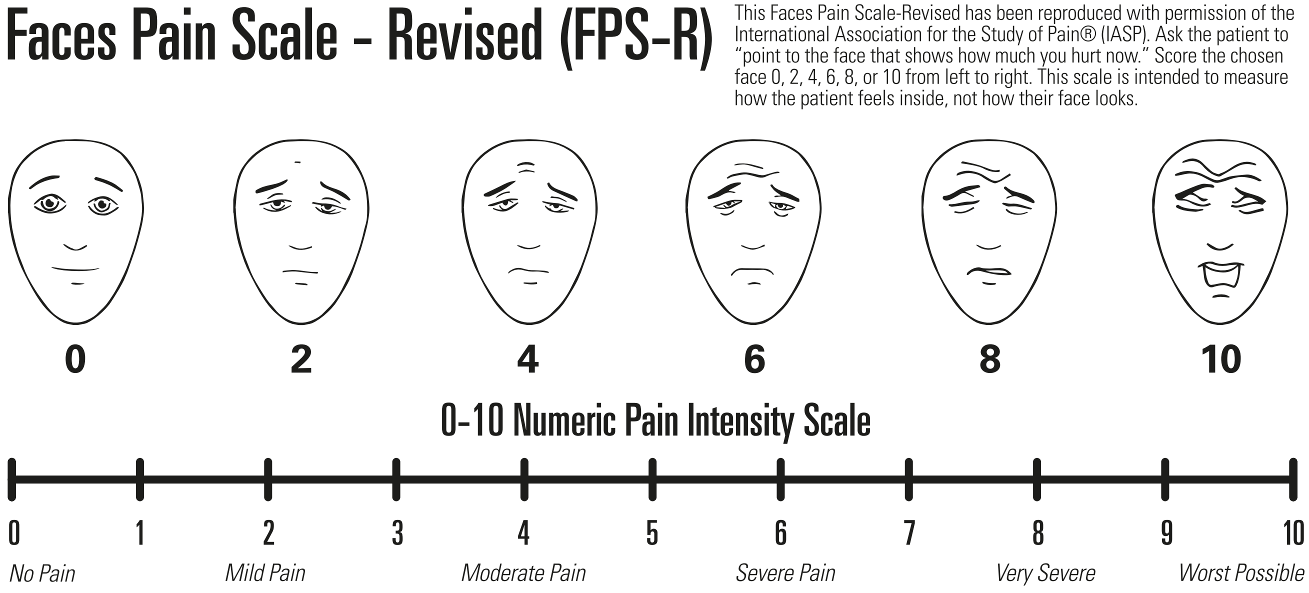
Although no one scale is appropriate or suitable for all patients, universal adoption of a 0–10 scale for clinical assessment of pain intensity in adult patients is recommended.[68,75] Standardization promotes collaboration and consistency in evaluation among caregivers across multiple settings (i.e., inpatient, ambulatory, home care/hospice or long-term care environments). Standardization also facilitates pain research through the collection of comparative data, allowing for simplification of data analyses. Detailed explanation of how to use a pain scale is necessary before patient use in any clinical care area.

Healthcare providers inconsistently use the word anchors on pain intensity scales. The intention behind the use of a word anchor to discriminate pain intensity is to provide a common endpoint. Some of the common word anchors that have been used are "worst possible pain," "pain as bad as it can be," "worst pain imaginable," "worst pain you have ever had," "most severe pain imaginable," and "most intense pain imaginable." Inconsistent or different word anchors may yield different pain reports. Therefore, it is important for healthcare professionals to achieve consensus about consistent use of word anchors in a particular setting.

Comparison of Pain Intensity Scales

Several studies have been systematically reviewed, and, although many are limited in sample size and population, a positive correlation has been demonstrated among the NRS, VDS, Wong–Baker FACES scale, and FPS-R.[29] Each of these commonly used pain rating scales appears to be adequately valid and reliable as a measure of pain intensity in cancer patients, elders, and patients with mild to moderate degrees of cognitive impairment.[29]

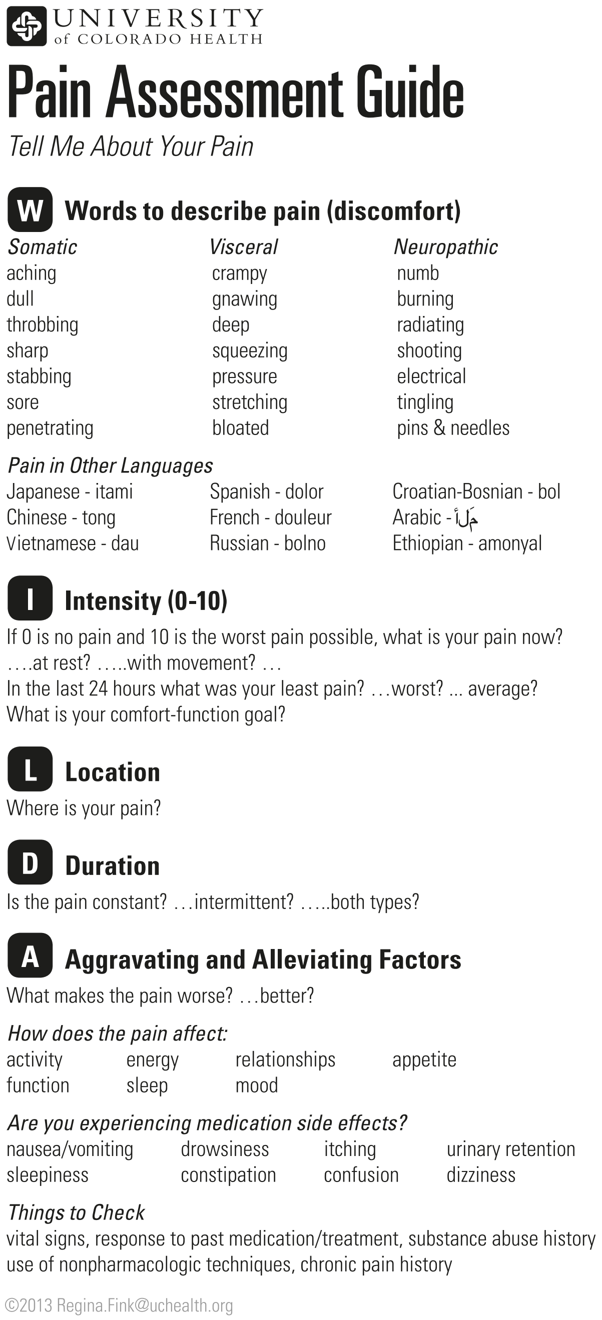
The use of a faces pain scale to measure pain intensity avoids language barriers and may cross cultural differences. Several faces pain scales have been used to assess pain in both pediatric and adult populations. A systematic review of commonly used faces scale for self-report of pain intensity in children recommended that the FPS-R be used in research studies[73]; however, there were no recommendations for using one faces scale over another in clinical use, and there is no consensus as to the type of faces scale to use in the palliative care setting. The literature regarding pain scale choice among ethnic groups is equivocal. Elderly long-term care residents of various ethnicities were asked to choose which of three pain intensity scales (NRS, VDS, and FPS) they preferred to use to rate their pain. Of those able to choose, the VDS was the most commonly selected (52%), more men than women and those residents with moderate to severe pain preferred the NRS; a higher percentage of minority (Latino) residents preferred the FPS.[76] Participants clearly agreed that the FPS represented pain but also agreed that the FPS may represent other constructs, such as sadness or anger, depending on how they were cued; this may suggest that the FPS may be measuring pain affect, not just intensity. Ware et al. recommend consideration of the FPS-R when repeat assessments are indicated in older cognitively impaired minority adults.[77] While the FPS-R is generally favored for *both* cognitively intact and cognitively impaired older adults, it should be noted that the FPS-R may not clearly represent pain intensity only but may also represent a broader construct "pain affect."[77] In addition, Ware et al. found that Latino patients preferred the FPS-R over the vertical pain thermometer and other instruments used to measure pain intensity.[77]


Faces Pain Scale - Revised (FPS-R)

This Faces Pain Scale-Revised has been reproduced with permission of the International Association for the Study of Pain® (IASP). Ask the patient to "point to the face that shows how much you hurt now." Score the chosen face 0, 2, 4, 6, 8, or 10 from left to right. This scale is intended to measure how the patient feels inside, not how their face looks.

Figure 8.1 WILDA card, page 2.

Source: References 66, 67. Used with permission.



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Pain Assessment Guide

Tell Me About Your Pain

W Words to describe pain (discomfort)

Somatic	*Visceral*	*Neuropathic*
aching	crampy	numb
dull	gnawing	burning
throbbing	deep	radiating
sharp	squeezing	shooting
stabbing	pressure	electrical
sore	stretching	tingling
penetrating	bloated	pins & needles

Pain in Other Languages

Japanese - itami
Chinese - tong
Vietnamese - dau
Spanish - dolor
French - douleur
Russian - bolno
Croatian-Bosnian - bol
Arabic - ألَم
Ethiopian - amonyal

I Intensity (0-10)

If 0 is no pain and 10 is the worst pain possible, what is your pain now?
….at rest? …..with movement? …
In the last 24 hours what was your least pain? …worst? ... average?
What is your comfort-function goal?

L Location

Where is your pain?

D Duration

Is the pain constant? …intermittent? …..both types?

A Aggravating and Alleviating Factors

What makes the pain worse? …better?

How does the pain affect:

activity
function
energy
sleep
relationships
mood
appetite

Are you experiencing medication side effects?

nausea/vomiting
sleepiness
drowsiness
constipation
itching
confusion
urinary retention
dizziness

Things to Check

vital signs, response to past medication/treatment, substance abuse history
use of nonpharmacologic techniques, chronic pain history

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Figure 8.1 Continued

In summary, a variety of scales have been used to assess pain in varied patient populations. Each has been widely used in clinical research and practice. Little research has been done on the appropriateness of pain scales in the palliative care setting. Intellectual understanding and language skills are prerequisites for pain assessment scales such as the VDS. These scales may be too abstract or too difficult for palliative care patients. Because most dying patients are elderly, simple pain scales, such as the NRS or a faces scale, may be more advantageous.

Multidimensional Pain Instruments

Several multidimensional pain measurement instruments are used in clinical and research settings to standardize pain assessment and incorporate patient demographic factors, pain severity scales, pain descriptors, pain influence on function, and other questions related to pain. Five key instruments are briefly reviewed here.

Short Form-McGill Pain Questionnaire-2 (SF-MPQ-2)[78,79] The newest version of the SF-MPQ-2 (previous versions MPQ, MPQ-SF) is reliable, valid in older and younger people with cancer pain, and available in multiple languages. It includes 22 words to describe pain (each word or phrase is rated on an NRS [0 = none, 10 = worst possible pain]) with two additional pain measures: the Present Pain Intensity Index (PPI) and overall intensity of total pain experience (no pain – mild – discomforting – distressing – horrible – excruciating).

Brief Pain Inventory-Short Form (BPI-SF) [80] This is a 9-item self-administered survey used to evaluate the severity of a patient's

Table 8.6 Pain intensity scales

Scale	Description	Comments
Numeric rating scale (NRS)	Number provided on a 0–10 scale represents pain intensity 0=no pain 10=worst possible pain	◆ Gold standard for adult patients able to self-report ◆ May be used in children age 7 years or older ◆ Verbal administration enables visually impaired or those by phone to quantify pain intensity
Verbal descriptor scale (VDS)	Adjectives reflecting pain extremes are ranked in order of severity ◆ No pain ◆ Mild pain ◆ Moderate pain ◆ Severe pain ◆ Very severe pain ◆ Worst possible pain	◆ Easily comprehended by the elderly ◆ Each descriptor may correlate with a number to constitute pain intensity ◆ May be translated into multiple languages ◆ Less reliable in those who are illiterate and have limited English vocabulary
Faces pain scale-revised (FPS-R)	Six oval faces range from neutral (no pain) to a grimacing face (worst pain)	◆ Ease of use ◆ Oval-shaped faces without tears are adult-like in appearance and more acceptable by adults ◆ Facial expressions may be difficult to discern by those with visual difficulties ◆ Note: May measure other constructs instead of pain (e.g., depression, anger, distress)
Wong-Baker FACES scale (FACES)	Six cartoon-type faces range from a widely smiling face (no pain) to a face with tears (most pain)	◆ Easily visualized ◆ Ease of use by children ◆ Presence of tears on the most pain face may introduce bias when used with cultures not sanctioning crying.
Vertical pain thermometer (VPT)	Modified verbal descriptor scale that looks like a thermometer	◆ Increased sensitivity in elderly ◆ Ease of use is those with moderate to severe cognitive deficits
Visual analogue scale (VAS)	0–10 cm line 0–100 mm line	◆ Primarily used in research ◆ Reliable and valid ◆ Difficult to use in elderly, those with physical or visual disability ◆ Paper and pencil required ◆ Scoring is time-consuming

Source: Adapted from References 68–74.

pain and its impact on daily functioning. The patient is asked to rate his or her worst, least, average, and current pain intensity; list current treatments and their perceived relief; and rate the degree to which pain interferes with general activity, mood, walking ability, work, enjoyment of life, relations with other persons, and sleep on a 0–10 NRS. The BPI-SF is a modification of the Brief Pain Inventory–Long Form (32-items) and is available in multiple languages.

Memorial Pain Assessment Card (MPAC)[81] The MPAC is simple, valid, and consists of three VASs (pain intensity, pain relief, and mood), and a VDS with eight pain descriptors. It can be completed in less than 20 seconds and distinguishes between pain intensity, relief, and psychological distress.

American Pain Society Patient Outcomes Questionnaire-Revised (APS-POQ-R)[82] This 23-item, two-page survey was designed for quality improvement purposes. The questionnaire takes 10 minutes to complete, has established reliability and validity in adult hospitalized medical-surgical patients, and measures six aspects of quality: (1) pain severity and relief; (2) impact of pain on activity, sleep, and negative emotions; (3) side effects of treatment; (4) helpfulness of information about pain treatment; (5) ability to participate in pain treatment decisions; and (6) use of nonpharmacologic strategies. The use of this tool in palliative care populations has not been established.

***Edmonton Symptom Assessment System-revised* (ESAS-r)**[83] Since palliative care patients may experience concomitant symptoms, it is impossible to limit an assessment to the report of pain. Complications or symptoms related to the disease process, such as fatigue and anxiety, may exacerbate pain, or interventions to alleviate pain may cause side effects that result in new or worsening symptoms, such as constipation or nausea. The ESAS-r was developed to assist in the assessment of nine symptoms that are common in the palliative care setting: pain, tiredness, drowsiness, nausea, lack of appetite, depression, anxiety, shortness of breath, and well-being. There is also a blank scale for patient-specific symptoms. The ESAS was originally trialed in palliative care inpatients, and 83% of symptom assessments were completed by nurses or patients' family caregivers.[84] Tested in cognitively intact palliative care patients, the modified version, ESAS-r, is clearer in format; easier to understand with accompanying definitions describing the various symptoms, including pain; and specifies a timeframe of "now."[83] If patients are unable to complete the form or are unresponsive and incapable of self-report (final days of life), observer judgments become necessary and a space is provided for the person completing the assessment.

Nonverbal or Cognitively Impaired Patients

Patient's self-report, the gold standard for pain assessment, is not always feasible in those unable to verbalize pain and for patients with cognitive impairment (e.g., dementia and delirium). Impaired cognition and sensory losses are serious problems for the elderly, many patients with life-threatening illness, and for the majority of palliative care patients who may be imminently dying. These patients are all at increased risk for pain due to underassessment and undertreatment.[28,29] Patients who are nonverbal or cognitively impaired are often excluded from pain studies; thus, pain assessment and treatment in these groups are poorly understood.

Pain Behaviors

As noted by the IASP, "the inability to communicate verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment."[13] No single objective assessment strategy, such as interpretation of behaviors, determination of pathology, or estimates of pain by others, is sufficient by itself.[28] Nonverbal pain expression may complement, contradict, or replace the verbal complaint of pain. Pain behaviors may be a means of expressing or coping with pain. Behavioral cues can include anxiety, sleeplessness, inability to concentrate, and restlessness. Unfortunately, some of these behaviors or cues may relate to etiologies or symptoms other than pain. For example, insomnia caused by depression may complicate pain assessment.

It is not reasonable and is even inaccurate to assess pain by reliance on involuntary physiological bodily reactions, such as increases in blood pressure, pulse, or respiratory rate and depth. Elevated vital signs may occur with sudden, severe pain, but they usually do not occur with persistent pain after the body reaches physiological equilibrium.[34] The absence of behavioral or involuntary cues does not negate the presence of pain. Assessment of behavior for signs of pain during rest and movement may provide a potentially valid and reliable alternative to verbal and physiological indices of pain. Examples of pain behaviors in cognitively impaired or nonverbal patients or residents are displayed in Table 8.7.[10,24]

The *ASPMN Position Statement on Pain Assessment in the Patient Unable to Self-Report*[28] provides recommendations for assessing pain in special populations including nonverbal older adults with dementia and those who are intubated and/or unconscious.

Pain assessment and management can be guided by this hierarchy of pain assessment framework presented in Box 8.2.[21,28,29,34]

Assessing Pain in Dementia

The inability of patients with dementia to verbally communicate their pain makes them a vulnerable patient group, dependent on their caregivers. Knowing the life story of the patient, professional experience, teamwork based on good communication, and use of a pain assessment tool has been reported to improve pain relief at the end of life for patients with dementia.[85]

It has been proposed that the white matter lesions produced by vascular dementia may cause an increase in pain experience via central neuropathic pain mechanisms.[86] In addition, pain behaviors in individuals with dementia may be different from those of patients/residents who are cognitively intact. The relationship between pain and aggressive behavioral symptoms varies according to the communicative status of residents and disproportionately affects those who cannot articulate their pain. Strategies for enhancing pain management in these residents are needed to adequately treat pain and reduce aggression.[87] It has also been shown that patients/residents with increased levels of cognitive impairment may report less severe pain and patients with progressive dementia may have fewer pain complaints, which may be related to a diminished capacity or difficulty in communicating pain.[88] There is no consistent evidence to indicate that persons with dementia experience less pain sensation. Instead of being less sensitive to pain, older adults with dementia may not interpret sensations as painful.

Pain indicators in elderly demented patients identified by nursing home staff members include specific physical repetitive movements, facial expressions, vocal repetitions, physical signs of pain, and behavioral changes from the norm for that person. Observations of facial expressions may not be valid in patients with some types of dementia in which facial expressions are muted or in conditions that result in distorted facial expressions, such as Parkinson's disease or stroke.[88] A descriptive study examined ethnic differences in the presentation and intensity of nonverbal pain behaviors among African American, Caucasian, and Hispanic older adults with dementia when screened for pain by certified nursing assistants and found no significant differences in overall

Table 8.7 Pain behaviors

Behavior	Manifestation
Verbalizations	Saying common phrases: "Help me," "Ouch," "Don't touch me," "Stop hurting me," "Leave me alone" during activity such as positioning, movement, or bathing
Vocalizations	Moaning, groaning, crying, oohing, aahing, calling out, screaming, shouting, sighing, breathing heavily
Facial expressions	Grimace, frown, wince, frightened or sad look, closed eyes or rapid blinking, wrinkled or furrowed brow, tight jaw, clenched teeth
Changes in activity or movement	Posturing, splinting, bracing, guarding a body part, rubbing a painful area, pacing, rocking, withdrawing, lying still in bed, constant or intermittent shifting of position, resisting care
Mental status changes	Restless, agitated, jittery, distress, confusion

Source: Adapted from References 10, 24.

Box 8.2 Hierarchy of Pain Assessment and Treatment in the Nonverbal or Cognitively Impaired

1. Use the hierarchy of pain assessment techniques:
    a. Obtain self-report, if possible.
    b. Search for potential causes of pain or other pathologies that could cause pain.
    c. Observe patient behaviors that are indicative of pain.
    d. Obtain proxy reporting (family members, parents, caregivers) of pain and behavior/activity changes.
    e. Attempt an analgesic trial to assess a reduction in possible pain behaviors.
2. Establish a procedure for pain assessment.
3. Use behavioral pain assessment tools, as appropriate.
4. Minimize emphasis on physiologic indicators such as vital signs.
5. Reassess and document.

Source: Adapted from References 21, 28, 29, 34.

Box 8.3 Checklist: Pain Assessment and Management in the Nonverbal or Cognitively Impaired Patient or Resident

- Is there a reason for the patient to be experiencing pain? Review the patient's diagnoses and investigate reason for any new pain.
- Was the patient previously treated for pain? If so, what regimen was effective (include pharmacologic and nonpharmacologic interventions)?
- How does the patient usually act when he/she is in pain? (Note: the nurse may need to ask family/significant others or other healthcare professionals.)
- What is the family caregiver's interpretation of the patient's behavior? Does he or she think the patient is in pain? Why does he or she feel this way?
- Try to obtain feedback from the patient; for example, ask patient to nod head, squeeze hand, move eyes up or down, raise legs, or hold up fingers to signal presence of pain.
- If appropriate, offer writing materials or pain intensity charts that patient can use.
- If there is a possible reason for or sign of acute pain, treat with analgesics or other pain-relief measures.
- If a pharmacologic or nonpharmacologic intervention results in modifying pain behavior, continue with treatment.
- If pain behavior persists, rule out potential causes of the behavior (delirium, side effect of treatment, symptom of disease process); try appropriate intervention for behavior cause.
- Explain interventions to patient and family caregiver.

pain intensity noted across ethnic groups. These findings are the first to examine ethnic differences in nonverbal pain behaviors for older adults with dementia.[89]

Behavior or responses caused by noxious stimuli in individuals with dementia may not necessarily reflect classic or typical pain behaviors. There is considerable variability and uniqueness in behavior expressions of pain in nonverbal older adults with dementia.[88] For example, pain may be exhibited by withdrawn behavior, aggressive behavior, or verbally abusive behavior. In a study of 26 patients with painful conditions from a nursing home Alzheimer's unit, Marzinski[90] reported diverse responses to pain that were not typical of conventional pain behaviors. For example, a patient who normally moaned and rocked became quiet and withdrawn when experiencing pain; pain in another nonverbal patient caused rapid blinking. Other patients who normally exhibited disjointed verbalizations could, when experiencing pain, give accurate descriptions of their pain. A checklist (refer to Box 8.3) can be used as a template for assessment and treatment of pain in the nonverbal or cognitively impaired patient/resident.

Instruments to Assess Pain in Nonverbal or Cognitively Impaired Patients

Pain Behavioral Scales

Assessing pain in patients/residents who are nonverbal or cognitively impaired and are unable to verbally self-report pain presents a particular challenge to clinicians. An instrument that could detect the presence of or a reduction in pain behaviors could facilitate effective pain management plans. However, because pain is not just a set of pain behaviors, the absence of certain behaviors does not necessarily mean that the patient is pain free. As evident from several excellent reviews of pain tools,[28,29,91] many healthcare providers and researchers have attempted to develop easy-to-use, valid, and reliable instruments for the assessment of pain in this vulnerable population. Currently, there is no one specific tool based on nonverbal pain behaviors that can be recommended for general applicability in clinical practice, special populations, and palliative care settings. A basic summary of common instruments used to assess pain in populations unable to self-report is found in Table 8.8.[92–100] Herr and colleagues[28] have performed an extensive and critical evaluation of many of these existing tools (conceptualization, subject/setting, reliability and validity data based on research, administration/scoring methods, strengths/weaknesses) with the intent of providing up-to-date information to clinicians and researchers as it becomes available. These detailed reviews can be accessed at http://prc.coh.org/pain_assessment.asp.

Proxy Pain Assessment in the Nonverbal or Cognitively Impaired

Just as the experience of pain is subjective, observing and interpreting a patient's/resident's pain is a subjective experience. Without verbal validation from the patient, the clinician must rely not only on behavioral observations but also on intuition and personal judgment. It is also particularly important to elicit the opinions of those individuals closest to the patient, which are also subjective.

Nurses and other healthcare providers reflect the difficulty of accurately assessing pain in nonverbal or cognitively impaired patients in studies that show low concurrence between patients' self-ratings of pain and clinicians' ratings.[101] Other findings are equivocal, with some studies suggesting that family caregivers or significant

Table 8.8 Pain instruments for populations unable to self-report

Instrument	Population	Description
Behavioral Pain Scale (BPS)	Critically ill, intubated patients	Each of 3 dimensions scored (1–4) for a total score (3 = no pain to 12 = maximum pain) Facial expression 1. Relaxed 2. Partially tightened 3. Fully tightened 4. Grimacing Upper limb movements 1. No movement 2. Partially bent 3. Fully bent 4. Permanently retracted Compliance with mechanical ventilation 1. Tolerating movement 2. Coughing but tolerating ventilation most of the time 3. Fighting ventilator 4. Unable to control ventilation
Critical Care Pain Observation Tool (CPOT)	Critical care patients	Each of 4 domains scored from 0–2 for total score (0–8) ◆ Facial expression ◆ Body movements ◆ Patient compliance with the ventilator (intubated) or vocalization (extubated) ◆ Muscle tension Pain is suspected when score >2 or increases by 2 or more.
Checklist of Nonverbal Pain Indicators (CNPI)	Cognitively impaired elders	Rate absence (0) or presence (1 or 2) of 6 behaviors at rest and on movement for total score (0–12) ◆ Nonverbal vocalizations ◆ Facial grimace/wince ◆ Bracing ◆ Rubbing ◆ Restlessness ◆ Verbalization
FLACC-revised (FLACC-r)	Postoperative children, critical care patients, cognitively impaired adults	Each of 5 items scored from 0–2 for total score (0–10) ◆ Face ◆ Legs ◆ Activity ◆ Cry ◆ Consolability
Multi-dimensional Objective Pain Assessment Tool (MOPAT)	Non-communicative hospice patients	Behavioral dimension: 4 items scored (0 = none to 3 = severe) ◆ Restless ◆ Tense muscles ◆ Frowning/grimacing ◆ Patient sounds Physiologic dimension: scored no change from usual (0) or change from usual (1) ◆ Blood pressure ◆ Heart rate ◆ Respirations ◆ Diaphoresis Both dimensions summed for total pain score (0–16)

(continued)

Table 8.8 Continued

Instrument	Population	Description
Pain Assessment behavioral Scale (PABS)	Nonverbal hospitalized critically ill patients	Each of 5 items scored from 0–2 for a total score (0–10) ◆ Face ◆ Restlessness ◆ Muscle tone ◆ Vocalization ◆ Consolability Patient is observed at rest and with movement. Two scores are generated; higher score is documented.
Pain Assessment in Advanced Dementia (PAINAD)	Advanced dementia patients	Each of 5 items scored from 0–2 for a total score (0–10) ◆ Breathing (independent of vocalization) ◆ Negative vocalization ◆ Facial expression ◆ Body language ◆ Consolability

Source: Adapted from References 92–100.

others had difficulty assessing pain in their loved one[102] or accurately estimating the amount of pain cancer patients experience and others proposing that family caregivers overestimate patients' pain. Bruera and colleagues[103] studied relatives and nurses who cared for 60 unresponsive, dying patients. Both were asked to rate a patient's discomfort level using six observed behaviors (grimacing, groaning, shouting, touching or rubbing an area, purposeless movement, labored breathing) and the suspected reason for the discomfort. Although the mean levels of perceived discomfort were similar, relatives reported significantly more observed behaviors and more often indicated pain as a reason for discomfort than did the nurse caregivers. According to Cohen-Mansfield,[104] relatives of cognitively impaired nursing home residents are better able to interpret facial expressions and other pain behaviors if they visit their loved ones at least once a week and have a close relationship. To detect pain in cognitively impaired nursing home residents, it is essential for family members and certified nursing assistants to know the resident's usual behavior and patterns to be able to detect pain.

Implications for Treatment

Although pain assessment in the nonverbal or cognitively impaired patient or resident presents a challenge to clinicians, it should not pose a barrier to optimal pain management. If patients are no longer able to verbally communicate whether they are in pain or not, the best approach is to assume that their underlying disease is still painful and to continue pain interventions based on analgesic history.[30] A collaborative interdisciplinary palliative care team can optimize patient care and develop a plan of care.[105]

Nonverbal patients should be empirically treated for pain if there is preexisting pain or evidence that any individual in a similar condition would experience pain. Likewise, palliative measures should be considered in nonverbal patients with behavior changes potentially related to pain.

Conclusion

Multiple factors should be incorporated into the assessment of the pain experience. The case studies include some of the pain assessment techniques discussed in this chapter. A review of these cases may prove beneficial when nurses and other healthcare providers apply this content.

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CHAPTER 9

Pain Management

Judith A. Paice

Key Points

- Pain is highly prevalent in palliative care, yet the majority of individuals can obtain good relief with available treatment options.
- An awareness of barriers to adequate pain care allows palliative care nurses to assess for and to plan interventions to overcome these obstacles when caring for patients. Advocacy is a critical role of the palliative care nurse.
- Assessment of pain, including a thorough history and comprehensive physical exam, guides the development of the pharmacological and nonpharmacological treatment plan.
- Pharmacological therapies include nonopioids, opioids, adjuvant analgesics, nonpharmacological and integrative therapies, cancer treatment, and, in some cases, interventional techniques.
- Intractable pain and symptoms, although not common, must be treated aggressively. In some cases, palliative sedation may be warranted.

Introduction

Of the many symptoms experienced by those at the end of life, pain is one of the most common and most feared. However, this fear is largely unfounded because the majority of patients with terminal illness can obtain relief. Nurses are critical members of the palliative care team, particularly in providing pain management. The nurse's role begins with assessment and continues through the development of a plan of care and its implementation. During this process, the nurse provides education and counseling to the patient, family, and other team members. Nurses also are critical for developing institutional policies and monitoring outcomes that ensure good pain management for all patients within their palliative care program. To provide optimal pain control, all healthcare professionals must understand the frequency of pain at the end of life, the barriers that prevent good management, the assessment of this syndrome, and the treatments used to provide relief. Effective pain control and alleviation of suffering is highly dependent upon the strength of clinician, patient, and family communication and relationship. These are key strengths of nursing at all phases of palliative care.

Prevalence of Pain

The prevalence of pain in the terminally ill varies by diagnosis and other factors. Approximately one-third of persons who are actively receiving treatment for cancer and two-thirds of those with advanced malignant disease experience pain.[1] Individuals at particular risk for undertreatment include the elderly, minorities, and women. Almost three-quarters of patients with advanced cancer admitted to the hospital experience pain upon admission. In other studies of patients admitted to palliative care units, pain often is the dominant symptom, along with fatigue and dyspnea. Children dying of cancer also are at risk for pain and suffering.[2]

Unfortunately, there has been little characterization of the pain prevalence and experience of patients with other life-threatening disorders. However, those working in palliative care are well aware that pain frequently accompanies many serious illnesses, such as human immunodeficiency virus (HIV), multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), and end-stage renal disease (ESRD).[3–6] Furthermore, many patients in hospice and palliative care are elderly and more likely to have existing chronic pain syndromes, such as osteoarthritis or low back pain.[7]

Additional research is needed to fully characterize the frequency of pain and the type of pain syndromes seen in patients at the end of life. This information will lead to improved detection, assessment, and, ultimately, treatment. Unfortunately, pain continues to be undertreated even when prevalence rates and syndromes are well understood. The undertreatment is largely due to barriers related to healthcare professionals, the system, and patients and their families.[8]

Barriers to Pain Relief

Barriers to good pain relief are numerous and pervasive. Often, because of lack of education, misconceptions, or attitudinal issues, these barriers contribute to the significant numbers of patients who do not get adequate pain relief.[9] Careful examination of these barriers provides a guide for changing individual practice, as well as building an institutional plan within the palliative care program to improve pain relief (Box 9.1). Most studies address the barriers associated with cancer pain. Therefore, barriers facing individuals with other disorders commonly seen in palliative care are not well characterized. One might suggest that these individuals are affected to an even greater extent, as biases may be more pronounced in those with noncancer diagnoses.

Healthcare Providers

Fears related to opioids held by professionals lead to underuse of these analgesics, and this concern has been exacerbated by the exploding opioid misuse epidemic.[10] Numerous surveys have revealed that physicians, nurses, and pharmacists express concerns about addiction, tolerance, and side effects of morphine and related compounds.[11,12] This concern has increased as rates of misuse and

Box 9.1 Barriers to Cancer Pain Management

Problems related to healthcare professionals

Inadequate knowledge of pain management

Poor assessment of pain

Concern about regulation of controlled substances

Fear of patient addiction

Concern about side effects of analgesics

Concern about patients' becoming tolerant to analgesics

Problems related to the healthcare system

Low priority given to cancer pain treatment

Restrictive regulation of controlled substances

Problems of availability of treatment or access to it:

- Inadequate reimbursement
- Shortages of medications
- Limited availability of palliative care and pain specialists
- Limited access to addiction specialists for patients with substance use disorder
- Insufficient time

Problems related to patients

Reluctance to report pain

Concern about distracting physicians from treatment of underlying disease

Fear that pain means disease is worse

Concern about not being a "good" patient

Poor health literacy/challenges to adherence to analgesic regimen

Reluctance to take pain medications

Fear of addiction or of being thought of as an addict

Worries about unmanageable side effects

Concern about becoming tolerant to pain medications

Source: Adapted from References 9, 12.

even deaths due to recreational opioid use have increased in the community.[13] Inevitability of pain is also expressed, despite evidence to the contrary. Not surprisingly, lack of attention to pain and its treatment during basic education is frequently cited. Those providing care at the end of life must evaluate their own knowledge and beliefs, including cultural biases, and strive to educate themselves and their colleagues.

Healthcare Settings

Lack of availability of opioids is pervasive, affecting not only sparsely populated rural settings but also inner-city pharmacies reluctant to carry these medications.[14,15] Pain management continues to be a low priority in some healthcare settings, reimbursement for these services is poor, and, as a result, some settings lack qualified professionals with expertise in pain management.[16] All of this is complicated by the cost of analgesic treatments and lack of reimbursement by third-party payers.[17]

Patients and Families

Understanding these barriers will lead the professional to better educate and better counsel patients and their families. Since these fears are insidious, patients and family members or support persons should be asked if they are concerned about addiction and tolerance (often described as becoming "immune" to the drug by laypersons). Studies have suggested that these fears lead to undermedication and increased intensity of pain.[18] Concerns about being a "good" patient or belief in the inevitability of cancer pain lead patients to hesitate in reporting pain. In these studies, less educated and older patients were more likely to express these beliefs. Patients seeking active treatment may believe that admitting to pain or other symptoms may reduce their eligibility for clinical trials. Lack of adherence to the medication regimen, complicated by limited understanding, can lead to unrelieved pain.[19,20] Some patients and family members delay taking opioids, believing they are only for the dying.

At the end of life, patients may need to rely on family members or other support persons to dispense medications. Each person's concerns must be addressed or provision of medication may be inadequate. Studies suggest that little concordance exists between patients' and family members' beliefs regarding analgesics. The interdisciplinary team is essential here, with nurses, social workers, chaplains, physicians, volunteers, and others exploring the meaning of pain and possible barriers to good relief. Education, counseling, reframing, and spiritual support are imperative. Nurses are particularly well-trained to offer the education and "coaching" that has been shown to provide improved relief. Strategies to provide education and support have included print materials, Internet-based programs, telehealth programs, and videoconferencing to educate patients, particularly those in rural areas. Overall, patient education has resulted in modest improvements in pain outcomes.[21]

Effects of Unrelieved Pain

Although many professionals and laypersons fear that opioid analgesics lead to shortened life, there is significant evidence to the contrary. A large cohort study revealed that individuals experiencing chronic pain had a 10-year increased mortality.[22] It is likely that inadequate pain relief hastens death by increasing physiological stress, potentially diminishing immunocompetence, decreasing mobility, worsening proclivities toward pneumonia and thromboembolism, and increasing the work of breathing and myocardial oxygen requirements. For example, studies of men with prostate cancer reveal a significant association between pain interference scores and risk of death.[23,24] Furthermore, pain may lead to spiritual death as the individual's quality of life is impaired. Therefore, it is the professional and ethical responsibility of clinicians to focus on and attend to adequate pain relief for their patients and to properly educate patients and their caregivers about all analgesic therapies, including opioids.

Assessment and Common Pain Syndromes

Comprehensive assessment of pain is imperative. This must be conducted initially, regularly throughout the treatment, and during any changes in the patient's pain state. For a complete discussion of pain assessment, see Chapter 8.

Pharmacological Management of Pain in Advanced Disease

A sound understanding of pharmacotherapy in the treatment of pain is of great importance in palliative care nursing. First, this knowledge allows the nurse to contribute to and fully understand the comprehensive plan of care. Thorough understanding also allows the nurse to recognize and assess medication-related adverse effects, to understand drug–drug and drug–disease interactions, and to educate patients and caregivers regarding appropriate medication usage. This will assure a comfortable process of dying, both for the well-being of the patient and for the sake of those in attendance.

This section provides an overview of the most commonly used agents and some of the newer pharmaceutical agents available in the United States for the treatment of unremitting and recurrent pain associated with advanced disease. The intent of this section is to arm the reader with a fundamental and practical understanding of the medications that are (or should be) available in most contemporary care settings, emphasizing those therapies for which there is clear and convincing evidence of efficacy.

Since patients or family members are not always aware of the names of their medications, or they may bring pills to the hospital or clinic that are not in their original bottles, many web-based resources provide pictures that can assist the nurse in identifying the current analgesic regimen. These can be found at http://www.drugs.com/pill_identification.html or http://www.webmd.com/pill-identification/default.htm. Some of these programs are available as applications for mobile phones and tablets.

Nonopioid Analgesics

Acetaminophen

Acetaminophen has been determined to be one of the safest analgesics for long-term use in the management of mild pain or as a supplement in the management of more intense pain syndromes, yet questions regarding its analgesic efficacy have been raised. Acetaminophen (also abbreviated as APAP and referred to as paracetamol outside of North America) may be considered an adjunct to any chronic pain regimen. A recent Cochrane review of oral acetaminophen found no high-quality evidence to support or refute its use alone or in combination with opioids for cancer pain.[25,26] Reduced doses or avoidance of acetaminophen is recommended in the face of renal insufficiency or liver dysfunction.[27] A complete review of both prescribed as well as over-the-counter (OTC) medications taken by the patient is indicated.[28] Many OTCs contain acetaminophen, and patients may not be aware of the risk of overdose. An intravenous formulation of acetaminophen is currently available and has been studied in a variety of perioperative, postoperative, and acute care settings. A Cochrane review found that approximately 36% of patients experienced approximately 4 hours of effective analgesia.[29] Intravenous acetaminophen has also been used to treat fever in pediatric oncology.[30] Cost issues and lack of clear benefit over oral administration may preclude its use in palliative care.[31]

Nonsteroidal Anti-inflammatory Drugs

Nonsteroidal anti-inflammatory drugs (NSAIDs) affect analgesia by reducing the biosynthesis of prostaglandins, thereby inhibiting the cascade of inflammatory events that cause, amplify, or maintain nociception. These agents also appear to reduce pain by influences on the peripheral or central nervous system independent of their anti-inflammatory mechanism of action. This secondary mode of analgesic efficacy is poorly understood. The "classic" NSAIDs (e.g., aspirin or ibuprofen) are relatively nonselective in their inhibitory effects on the enzymes that convert arachidonic acid to prostaglandins. As a result, gastrointestinal (GI) ulceration, renal dysfunction, and impaired platelet aggregation are common.[32,33] The cyclooxygenase-2 (COX-2) enzymatic pathway is induced by tissue injury or other inflammation-inducing conditions. It is for this reason that there appears to be less risk of GI bleeding with use of the COX-2 selective NSAID celecoxib, at least during initial months of treatment[34] (Table 9.1).

The NSAIDs, as a class, are very useful in the treatment of many pain conditions mediated by inflammation, including those caused by cancer. The NSAIDs offer the potential advantage of causing minimal nausea, constipation, sedation, or other effects on mental functioning. Therefore, depending on the cause of pain, NSAIDs may be useful for moderate to severe pain control, either alone or as an adjunct to opioid analgesic therapy. The addition of NSAIDs to opioids has the benefit of potentially allowing the reduction of the opioid dose when sedation, confusion, dizziness, or other central nervous system effects of opioid analgesic therapy alone become burdensome.

Decreased renal function and liver failure are relative contraindications for NSAID use. Similarly, platelet dysfunction or other potential bleeding disorders contraindicate use of the nonselective NSAIDs due to their inhibitory effects on platelet aggregation, with resultant prolonged bleeding time. Cardiovascular risk associated with NSAIDs, including myocardial infarction and stroke, has been identified and appears to be higher in those with preexisting risk factors.[35,36] Cardiovascular risk appears to be dependent upon duration of use, with celecoxib risk associated with 30 days or more of continuous use, while with other NSAIDs, such as ibuprofen, the risk increases within 7 days of use.[37,38] Studies suggest that patients are often unaware of the adverse effects associated with these drugs and may use NSAIDs in a way that increases risk.[39]

Opioid Analgesics

As a pharmacological class, the opioid analgesics represent the most useful agents for the treatment of pain associated with advanced disease (Box 9.2). The opioids are nonspecific insofar as they decrease pain signal transmission and perception throughout the nervous system, regardless of the pathophysiology of the pain. Moderate to severe pain is the main clinical indication for the opioid analgesics.[9,40] Despite past beliefs that opioids were ineffective for neuropathic pain, these agents have been found to be useful in the treatment of this complex pain syndrome; however, higher doses are usually warranted. Other indications for opioid use include the treatment of dyspnea, reduction in diarrhea, use as an anesthetic adjunct, and as a form of prophylactic therapy in the treatment of opioid use disorder (OUD) (e.g., methadone or buprenorphine for those with a history of misuse of opioids).

Table 9.1 Acetaminophen and selected nonsteroidal anti-inflammatory drugs

Drug	Dose if patient > 50 kg	Dose if patient < 50 kg
Acetaminophen[a,b]	500–1,000 mg q4–6h oral; maximum 4,000 mg/24 hr (2,000–3,000 mg if used chronically) 1,000 mg q6h IV (given over 15-minute infusion); maximum 4,000 mg/24 hr	10–15 mg/kg q4h (oral) 15 mg/kg q6h; maximum 75 mg (IV) 15–20 mg/kg q4h (rectal)
Aspirin[a,b]	4,000 mg/24 hr maximum, given q4–6h	10–15 mg/kg q4h (oral)
		15–20 mg/kg q4h (rectal)
Ibuprofen[a,b]	2,400 mg/24 hr maximum, given q6–8h	10 mg/kg q6–8h (oral)
Naproxen[a,b]	1,000 mg/24 hr maximum, given q8–12h	5 mg/kg q8h (oral/rectal)
Choline magnesium trisalicylate[a,d]	2,000–3,000 mg/24 hr maximum, given q8–12h	25 mg/kg q8h (oral)
Indomethacin[b]	75–150 mg/24 hr maximum, given q8–12h	0.5–1 mg/kg q8–12h (oral/rectal)
Ketorolac[c]	30–60 mg IM/IV initially, then 15–30 mg q6h bolus IV/IM or continuous IV/SQ infusion; short-term use only (3–5 days)	0.25–1 mg/kg q6h short-term use only (3–5 days)
Celecoxib[d,e]	100–200 mg PO up to bid	No data available

[a] Commercially available in a liquid form.

[b] Commercially available in a suppository form.

[c] Potent anti-inflammatory (short-term use only due to gastrointestinal side effects).

[d] Minimal platelet dysfunction.

[e] Cyclooxygenase-2-selective nonsteroidal anti-inflammatory drug.

Box 9.2 Guidelines for the Use of Opioids

Clinical studies and experience suggest that adherence to some basic precepts will help optimize care of patients who require opioid analgesic therapy for pain control:

- Oral administration of opioids is preferred in most cases. Intramuscular administration is highly discouraged. Subcutaneous or intravenous delivery is an alternative.
- Noninvasive drug delivery systems that "bypass" the enteral route (e.g., the transdermal [fentanyl or buprenorphine] and the oral transmucosal routes for delivery of fentanyl for treatment of continuous pain and breakthrough pain) may obviate the necessity to use parenteral routes for pain control in some patients who cannot take medications orally or rectally.
- Anticipation, prevention, and treatment of sedation, constipation, nausea, psychotomimetic effects, and myoclonus should be part of every care plan for patients being treated with opioid analgesics.
- Changing from one opioid to another or one route to another is often necessary, so facility with this process is an absolute necessity. Remember the following points:
    - Incomplete cross-tolerance occurs, leading to decreased requirements of a newly prescribed opioid.
    - Use morphine milligram equivalents (MME) as a "common denominator" for all dose conversions in order to avoid errors.

Source: References 9, 40.

The only absolute contraindication to the use of an opioid is a history of a hypersensitivity reaction (rash, wheezing, and edema). In the rare event that a patient describes a true allergic reaction, one might begin therapy with a low dose of a short-acting synthetic opioid (e.g., intravenous fentanyl) or try an intradermal injection as a test dose. The rationale for using a synthetic opioid (preferably one without dyes or preservatives since these can cause allergic reactions) is that the prevalence of allergic reactions is much lower.

It is also critically important for clinicians who are involved in patient care to be aware that titration of opioid analgesics to affect pain relief is rarely associated with induced respiratory depression and iatrogenic death.[41,42] In fact, the most compelling evidence suggests that inadequate pain relief hastens death by increasing physiological stress, decreasing immunocompetence, diminishing mobility, increasing the potential for thromboembolism, worsening inspiration and thus placing the patient at risk for pneumonia, and increasing myocardial oxygen requirements. Furthermore, in several systematic reviews, there was no relationship between opioid use and survival.[43,44]

There is significant inter- and intraindividual variation in clinical responses to the various opioids, so, in most cases, a dose-titration approach should be viewed as the best means of optimizing care.[45] This implies that close follow-up is required to determine when clinical endpoints have been reached. Furthermore, idiosyncratic responses may require trials of different agents to determine the most effective drug and route of delivery for any given patient. Table 9.2 lists more specific suggestions regarding optimal use of opioids.

Another factor that needs to be considered with opioid analgesics is the potential to accumulate toxic metabolites, especially in the face of decreasing drug clearance and elimination

Table 9.2 Approximate equianalgesic doses of most commonly used opioid analgesics[a]

Drug	Parenteral route	Enteral route
Morphine[b]	10 mg	30 mg
Codeine	130 mg	200 mg (not recommended)
Fentanyl[c]	100 mcg	TIRF[c]
Hydrocodone[b]	Not available	30 mg
Hydromorphone[d]	1.5 mg	7.5 mg
Levorphanol[e]	2 mg acute, 1 chronic	4 mg acute, 1 chronic
Methadone[e]	See text	See text
Oxycodone[f]	Not available	20 mg

TIRF, transmucosal immediate-release fentanyl.

[a] Dose conversion should be closely monitored since incomplete cross-tolerance may occur.

[b] Available in continuous and sustained-release pills and capsules, formulated to last 12 or 24 hours

[c] Also available in transdermal and TIRF, see package insert materials for dose recommendations. TIRF = transmucosal immediate release fentanyl.

[d] Available as a continuous-release formulation lasting 24 hours.

[d] These drugs have long half-lives, so accumulation can occur; close monitoring during first few days of therapy is very important.

[f] Available in several continuous-release doses, formulated to last 12 hours.

Source: References 9, 40.

as disease progresses and organ function deteriorates. Due to its neurotoxic metabolite, normeperidine, meperidine use is specifically discouraged for chronic pain management. As well, the mixed agonist–antagonist agents, typified by butorphanol, nalbuphine, and pentazocine, are not recommended for the treatment of chronic pain. They have limited efficacy, and their use may cause an acute abstinence syndrome in patients who are otherwise using pure agonist opioid analgesics.

Morphine

Morphine is most often considered the "gold standard" of opioid analgesics and is used as a measure for dose equivalence (Table 9.2).[9,40] Although some patients cannot tolerate morphine due to itching, headache, dysphoria, or other adverse effects, common initial dosing effects such as sedation and nausea often resolve within a few days. In fact, one should anticipate these adverse effects, especially constipation, nausea, and sedation, and prevent or treat appropriately (see later discussion). Metabolites of morphine and hydromorphone, morphine-3-glucuronide (M3G) and hydromorphone-3-glucuronide (H3G), respectively, may contribute to myoclonus, seizures, and hyperalgesia (increasing pain), particularly when patients cannot clear these metabolites due to renal impairment.[46,47] However, in a small study of hospice patients, increased levels of either M3G or H3G were not correlated with the presence of myoclonus.[48] If adverse effects exceed the analgesic benefit of the drug, convert to an equianalgesic dose of a different opioid. Because cross-tolerance is incomplete, reduce the calculated dose by one-third to one-half and titrate upward based on the patient's report of relief and/or improved level of function.[9]

Morphine's bitter taste may be prohibitive, especially if "immediate-release" tablets are left in the mouth to dissolve. When patients have dysphagia, several options are available. The 24-hour, long-acting morphine capsule can be broken open and the "sprinkles" placed in applesauce or other soft food. Oral morphine solution can be swallowed, or small volumes (0.5–1 mL) of a concentrated solution (e.g., 20 mg/mL) can be placed in the mouth of patients whose voluntary swallowing capabilities are more significantly limited. Buccal uptake of morphine is slow, unpredictable, and insufficient to produce analgesia due to its hydrophilic nature.[49] Furthermore, again due to the hydrophilic nature of morphine, creams, gels, and patches that contain morphine do not cross the skin and therefore do not provide systemic analgesia.[50] Commercially prepared suppositories, compounded suppositories, or microenemas can be used to deliver the drug into the rectum. Sustained-release morphine tablets have been used rectally, with resultant delayed time to peak plasma level and approximately 90% of the bioavailability achieved by oral administration.[51]

Fentanyl

Fentanyl is a highly lipid soluble opioid that has been administered parenterally, spinally, transdermally, transmucosally (buccal, sublingual, and nasal), and by nebulizer for the management of dyspnea. Because of its potency, dosing is usually conducted in micrograms.

Transdermal Fentanyl

Transdermal fentanyl, often called the fentanyl patch, is particularly useful when patients cannot swallow, do not remember to take medications, or have adverse effects to other opioids. Two primary systems are currently available—a reservoir-based patch and a matrix type patch. These systems exhibit quite similar effects in intact skin, although differences may result when exposed to heat (greater drug permeation at 72 hours in the reservoir system) or to compromised skin (greater permeation seen in the matrix patch).[52] Although the package insert states that transdermal patches should not be used in opioid-naive patients, a small study suggests that the 12 mcg/hr patch can be safely used in this population.[53] Fever, diaphoresis, cachexia, morbid obesity, liver function, ascites, and the concomitant use of 3A4 inducers may have an impact on the absorption, predictability of blood levels, and clinical effects of transdermal fentanyl.[54] One study comparing cachectic with normal weight patients found reduced serum fentanyl levels in those with reduced weight.[55] Despite these lower levels, clinical experience reveals that transdermal fentanyl can be effective even in those patients with few fat stores. Higher doses may be indicated. There is some suggestion that transdermal fentanyl may produce less constipation when compared to long-acting morphine.[56] At lower doses, transdermal fentanyl has limited effect on the sphincter of Oddi, suggesting that this may be a safe and effective therapy for patients with pancreatitis.[57]

Some patients experience decreased analgesic effects after only 48 hours of applying a new patch; a more frequent (q48h) patch change should be scheduled. As with all long-acting preparations, breakthrough pain medications should be made available to patients using continuous-release opioids such as the fentanyl patch.

Transmucosal Immediate Release Fentanyl Products

Several formulations of transmucosal immediate-release fentanyl (TIRF) products are available, including oral transmucosal fentanyl citrate (OTFC), buccal tablets, and soluble film, as well as oral and nasal spray.[58] Adults should start with the lowest dose and monitor efficacy, advancing to higher dose units as needed. Clinicians must be aware that, unlike other breakthrough pain drugs, the around-the-clock dose of opioid does not predict the effective dose of OTFC. Fentanyl nasal spray has the most rapid onset of the TIRF products, with significantly improved pain intensity scores as early as 5 minutes after administration, along with minimal adverse effects.[59]

Oxycodone

Oxycodone is a synthetic opioid available in a long-acting formulation, as well as in immediate-release tablets (alone or with acetaminophen, aspirin, or ibuprofen) and liquid. It is approximately as lipid soluble as morphine but has better oral absorption. The equianalgesic ratio is approximately 20 mg to 30 mg of oral morphine. Side effects appear to be similar to those experienced with morphine.[60] Substances that inhibit CYP3A4, such as the highly active antiretroviral agent ritonavir, the antiviral voriconazole, and even grapefruit juice, have been found to increase oxycodone concentrations.[61] Lower doses of oxycodone may be warranted when CYP3A4 inhibitors are administered.

Methadone

Methadone has several characteristics that make it useful in the management of severe, chronic pain. The half-life of 24–60 hours or longer allows prolonged dosing intervals, although for pain control, dosing every 8–12 hours is recommended. Methadone may also bind as an antagonist to the *N*-methyl-D-aspartate (NMDA) receptor, believed to be of particular benefit in neuropathic pain and in preventing hyperalgesia. Additionally, methadone can be given orally, parenterally, and sublingually. Furthermore, methadone is much less costly than comparable doses of proprietary continuous-release formulations, making it potentially more available for patients without sufficient financial resources for more costly drugs.[62]

Despite these advantages, much is unknown about the appropriate dosing ratio between methadone and morphine, as well as the safest and most effective time course for conversion from another opioid to methadone (Table 9.2). As a result, recommendations suggest that patients be started on no more than 30–40 mg of methadone per day with very slow upward titration. Methadone should not be used for breakthrough pain dosing or on an as-needed basis.[63] Furthermore, although the long half-life is an advantage, it also increases the potential for drug accumulation before achieving steady-state blood levels, putting patients at risk for oversedation and respiratory depression. For example, it would take 12 days to reach steady state when the half-life is 60 hours. Close monitoring of these potentially adverse or even life-threatening effects is required, and most experts suggest that methadone only be prescribed by experienced clinicians.[63,64] Myoclonus has been reported with parenteral methadone use.[65] Of concern for some patients is the prolongation of QT wave (also called torsade de pointes) that can occur with methadone administration.[66]

Methadone is metabolized by CYP3A4, CYP2D6, and other enzymes. As a result, drugs that induce CYP enzymes accelerate the metabolism of methadone, resulting in reduced serum levels of the drug (Table 9.3). This may be demonstrated clinically by shortened analgesic periods or reduced overall pain relief. Examples of these drugs often used in palliative care include several antiretroviral agents, dexamethasone, carbamazepine, phenytoin, and barbiturates.[67] Drugs that inhibit CYP enzymes slow methadone metabolism, potentially leading to sedation and respiratory depression. These include ketoconazole, omeprazole, and selective serotonin reuptake inhibitor (SSRI) antidepressants such as fluoxetine, paroxetine, and sertraline.

Table 9.3 Selected medications that increase or decrease methadone serum levels

CYP3A4 inducers that decrease methadone	CYP3A4 inhibitors that increase methadone
Barbiturates	Cimetidine
Carbamazepine	Ciprofloxacin
Dexamethasone	Diazepam
Phenytoin	Haloperidol
Rifampin	Ketoconazole
Spironolactone	Omeprazole
	Verapamil

Patients currently receiving methadone as part of a maintenance program for addictive disease will have developed cross-tolerance to the opioids and, as a result, require higher doses than naive patients. Prescribing methadone for substitution therapy in addictive disease requires a special license in the United States.

Hydromorphone

Hydromorphone is a useful alternative when synthetic opioids provide an advantage. It is available in oral tablets, liquids, suppositories, parenteral formulations, and a long-acting formulation.[68] Although hydromorphone-3-glucuronide may accumulate in renal disease, this metabolite is removed when patients are receiving dialysis, providing evidence for the safety of this drug in these patients.[69]

Oxymorphone

Oxymorphone is a semi-synthetic opioid that has been available in a parenteral formulation for almost 50 years and had been available in oral immediate-release and extended-release formulations since 2006.[70] The safety and efficacy profile in people with cancer is similar to other opioids, such as morphine and oxycodone.[71] An outbreak of oxymorphone injection that led to multiple new diagnoses of HIV infection within a small town in Indiana raised concerns regarding misuse of the opioid; the manufacturer voluntarily withdrew the extended-release formulation from the market.[72]

Other Opioids

Buprenorphine, codeine, hydrocodone, levorphanol, tramadol, and tapentadol are other opioids available in the United States for treatment of pain. Their equianalgesic comparisons are shown in Table 9.2. Buprenorphine, a partial agonist, is typically used as part of an opioid maintenance program instead of methadone. A 7-day buprenorphine patch approved for moderate to severe pain is now available in the United States.[73] Codeine is limited by pharmacogenetics; as a prodrug, it must be broken down by the enzyme CYP2D6 to provide analgesia, yet approximately 10% of Caucasians in the United States are poor metabolizers.[74]

Conversely, some patients are ultrarapid metabolizers, which can lead to overdose.[75] Hydrocodone is only available in combination products in its immediate-release form, thus limiting dose escalation in palliative care due to concerns regarding excess acetaminophen or other agents. There are single-agent, long-acting hydrocodone products that are administered daily or every 12 hours.[76] Levorphanol has similarities to methadone, including a longer half-life; it is difficult to obtain in the United States.[77] Tramadol is a weak opioid and has serotonin and norepinephrine reuptake inhibition properties. It is available in immediate- and extended-release formulations. Although effective for mild, nonmalignant, neuropathic pain, a systematic review found insufficient data to support its use for cancer pain.[78] Dose escalation is limited due to potential lowering of the seizure threshold, and clinicians must be alert to the risk of serotonin syndrome. Tapentadol is available in immediate- and extended-release formulations, and reports suggest it may be useful in some palliative care settings, particularly in the relief of neuropathic pain.[70,79]

Alternative Routes of Administration for Opioid Analgesics

Many routes of administration are available when patients can no longer swallow or when other dynamics preclude the oral route or favor other routes. These include transdermal, transmucosal (buccal, sublingual or nasal), rectal, enteral, vaginal, epidural, and intrathecal. In a study of cancer patients at 4 weeks, 1 week, and 24 hours before death, the oral route of opioid administration was continued in 62%, 43%, and 20% of patients, respectively. More than half of these patients required more than one route of opioid administration. As patients approached death and oral use diminished, the use of intermittent subcutaneous injections and intravenous or subcutaneous infusions increased.

Thus, in the palliative care setting, nonoral routes of administration must often be available. Enteral feeding tubes can be used to access the gut when patients can no longer swallow. The size of the tube should be considered when administering long-acting morphine or oxycodone "sprinkles" to avoid obstruction of the tube. The rectum, stoma, or vagina can be used to deliver medication. Thrombocytopenia, neutropenia, or painful lesions may preclude the use of these routes. Additionally, delivering medications via these routes can be difficult for family members, especially when the patient is obtunded or unable to assist. As previously discussed, transdermal, transmucosal, or buccal fentanyl are useful alternatives to these techniques.

Parenteral administration includes subcutaneous and intravenous delivery (intramuscular opioid delivery is inappropriate in the palliative care setting). The intravenous route provides rapid drug delivery but requires vascular access, placing the patient at risk for infection and potentially complicating the care provided by family or other loved ones. Subcutaneous boluses have a slower onset and lower peak effect when compared with intravenous boluses. Subcutaneous infusions may total up to 10 mL/hr (although most patients absorb 2–3 mL/hr with least difficulty). Volumes greater than 10 mL/hr are poorly absorbed. Hyaluronidase has been reported to speed absorption of subcutaneously administered drugs.

Intraspinal routes, including epidural or intrathecal delivery, may allow administration of drugs, such as opioids, local anesthetics, α-adrenergic agonists, or ziconitide.[80] One randomized controlled trial demonstrated benefit for cancer patients experiencing pain.[81] However, the equipment used to deliver these medications is complex, requiring specialized knowledge for healthcare professionals and potentially greater caregiver burden. Risk of infection is also of concern. Furthermore, cost is a significant concern related to high-technology procedures.

Preventing and Treating Adverse Effects of Opioid Analgesics

- *Constipation*. Patients in palliative care frequently experience constipation, in part due to opioid therapy.[82] Always begin a prophylactic bowel regimen when commencing opioid analgesic therapy.[40] Most clinicians recommend a laxative/softener combination, although a randomized controlled trial found that senna plus placebo was more effective than senna and docusate.[83] Avoid bulking agents (e.g., psyllium) since these tend to cause a larger, bulkier stool, increasing desiccation time in the large bowel. Furthermore, debilitated patients can rarely take in sufficient fluid to facilitate the action of bulking agents. Fluid intake should be encouraged whenever feasible. Senna tea and fruits may be of use. Several agents have been approved to address opioid-induced constipation (OIC). Several peripherally acting mu-opioid receptor antagonists (PAMORAs) are available, including subcutaneous and oral formulations (namely methylnaltrexone and naloxegal).[84,85] Lubiprostone, an oral agent that works on chloride channels in the intestine, was approved for use in opioid-induced constipation in noncancer patients.[86] For a more comprehensive review of bowel management, refer to Chapter 14.
- *Sedation*. Excessive sedation may occur with the initial exposure to opioids.[87] If sedation persists after 24–48 hours and other correctable causes have been identified and treated if possible, opioid rotation or the addition of psychostimulants may be beneficial. Psychostimulants include dextroamphetamine 2.5–5 mg orally every morning and midday or methylphenidate 5–10 mg orally every morning and 2.5–5 mg midday (although higher doses are frequently used). Adjust both the dose and timing to prevent nocturnal insomnia and monitor for undesirable psychotomimetic effects (such as agitation, hallucinations, and irritability). Little research is available to guide the use of these agents. Modafinil, an agent approved to manage narcolepsy, has been reported to relieve opioid-induced sedation with once-daily dosing. However, a randomized controlled trial found no effect on cancer-related fatigue compared with placebo.[88] Because of the lack of data regarding these agents, selection of drug and dosing are empirical.
- *Respiratory depression*. Respiratory depression is rarely a clinically significant problem for opioid-tolerant patients in pain. When respiratory depression occurs in a patient with advanced disease, the cause is usually multifactorial. Therefore, other factors beyond opioids need to be assessed, although opioids are frequently blamed for the reduced respirations. When undesired, depressed consciousness occurs along with a respiratory rate of less than 8/min or hypoxemia (O_2 saturation <90%) associated with opioid use, cautious and slow titration of naloxone, which reverses the effects of the opioids, should be instituted.[40] Excessive administration may cause abrupt opioid reversal with pain and autonomic crisis. Dilute 1 ampule of naloxone (0.4 mg/mL) in 10 mL of injectable saline (final concentration 40 mcg/mL) and inject 1 mL every 2–3 minutes

while closely monitoring the level of consciousness and respiratory rate.[40] Because the duration of effect of naloxone is approximately 30 minutes, the depressant effects of the opioid will recur at 30 minutes and persist until the plasma levels decline (often 4 or more hours) or until the next dose of naloxone is administered.

- *Nausea and vomiting*. Nausea and vomiting are common with opioids due to activation of the chemoreceptor trigger zone in the medulla, vestibular sensitivity, and delayed gastric emptying, but habituation occurs in most cases within several days.[87] Assess for other treatable causes. In severe cases or when nausea and vomiting are not self-limited, pharmacotherapy is indicated. See Chapter 12 for a thorough discussion of the assessment and treatment of nausea and vomiting.
- *Myoclonus*. Myoclonic jerking occurs more commonly with high-dose opioid therapy, although it has also been reported with lower dosing.[65,89] A lower relative dose of the substituted drug may be possible due to incomplete cross-tolerance, which might result in decreased myoclonus. Clonazepam 0.5–1 mg orally every 6–8 hours, to be increased as needed and tolerated, may be useful in treating myoclonus in patients who are still alert, able to communicate, and take oral preparations. Lorazepam can be given sublingually, if the patient is unable to swallow. Otherwise, parenteral administration of a benzodiazepine, such as midazolam, is indicated if symptoms are distressing.
- *Pruritus*. Pruritus appears to be most common with morphine, in part due to histamine release, but can occur with most opioids. Fentanyl and oxymorphone may be less likely to cause histamine release. Most antipruritic therapies cause sedation, so this side effect must be viewed by the patient as an acceptable tradeoff. Antihistamines (such as diphenhydramine) are the most common first-line approach to this opioid-induced symptom when treatment is indicated.[90] Ondansetron has been reported to be effective in relieving opioid-induced pruritus, but no randomized controlled studies exist.[91] See Chapter 20 for more information regarding pruritus.

Adjuvant Analgesics

A wide variety of nonopioid medications from several pharmacological classes have been demonstrated to reduce pain caused by various pathological conditions (Table 9.4). As a group, these drugs have been called analgesic "adjuvants," but this is something of a misnomer since they often reduce pain when used alone. However, under most circumstances, when these drugs are indicated for the treatment of severe neuropathic pain or bone pain, opioid analgesics are used concomitantly to provide adequate pain relief.

Antidepressants

The mechanism of the analgesic effect of tricyclic antidepressants appears to be related to inhibition of norepinephrine and serotonin.[92] The tricyclic antidepressants are generally believed to provide relief from neuropathic pain.[93] Side effects often limit the use of these agents in palliative care. Cardiac arrhythmias, conduction abnormalities, narrow-angle glaucoma, and clinically significant prostatic hyperplasia are relative contraindications to the tricyclic antidepressants. The delay in onset of pain relief, from days to weeks, may preclude the use of these agents for pain relief in end-of-life care. However, their sleep-enhancing and mood-elevating effects may be of benefit.

Both older antidepressants and newer atypical agents have been shown to be effective in relieving neuropathic pain, although there remains little support for the analgesic effect of SSRIs. Atypical antidepressants venlafaxine and duloxetine have been shown to reduce neuropathy associated with chemotherapy-induced neuropathy.[94]

Antiepilepsy Drugs

The older antiepilepsy or anticonvulsant drugs, such as carbamazepine and clonazepam, relieve pain by blocking sodium channels. Previously referred to as membrane stabilizers, these compounds are useful in the treatment of neuropathic pain, especially in those with episodic, lancinating qualities. Gabapentin and pregabalin act at the alpha-2 delta subunit of the voltage-gated calcium channel.[92] Additional evidence supports the use of these agents in neuropathic pain syndromes seen in palliative care, such as thalamic pain, pain due to spinal cord injury, and cancer pain, along with restless leg syndrome.[93] In a study comparing amitriptyline, gabapentin, and pregabalin in cancer patients with neuropathic pain, no significant differences were found in analgesic effect, although pregabalin had a greater morphine sparing effect.[95] Both gabapentin and pregabalin require dose reduction in ESRD.[96] Other anticonvulsants have been used with success in treating neuropathies, including lamotrigine, levetiracetam, tiagabine, topiramate, and zonisamide, yet no randomized controlled clinical trials are currently available.

Corticosteroids

Corticosteroids inhibit prostaglandin synthesis and reduce edema surrounding neural tissues. Dexamethasone has been found to reduce postoperative pain and nausea and is particularly useful for relieving painful neuropathic syndromes, including plexopathies, as well as pain associated with stretching of the liver capsule due to metastases.[97,98] Corticosteroids are also highly effective for treating bone pain due to their anti-inflammatory effects, as well as pain flair after radiation treatment of bone metastases.[99] Dexamethasone has been found to be useful in relieving symptoms associated with malignant intestinal obstruction.[100] Dexamethasone produces the least amount of mineralocorticoid effect, leading to reduced potential for Cushing's syndrome. Dexamethasone is available in oral, intravenous, subcutaneous, and epidural formulations. The standard dose is 2 to 24 mg/day and can be administered once daily due to the long half-life of this drug. Dexamethasone doses as high as 100 mg may be given with severe pain crises. Intravenous bolus doses should be pushed slowly, to prevent uncomfortable perineal burning and itching. An additional benefit of steroid use was revealed by a recent clinical trial in cancer patients that supported the use of dexamethasone in the relief of fatigue.[101]

Local Anesthetics

Local anesthetics work in a manner similar to the older anticonvulsants—by inhibiting the movement of ions across the neural membrane. They are useful for relieving neuropathic pain. Local anesthetics can be given orally, topically, intravenously, subcutaneously, or spinally. Mexiletine has been reported to be useful when anticonvulsants and other adjuvant therapies have failed, although high-quality studies are lacking. Local anesthetic gels and patches have been used to prevent the pain associated with needle

Table 9.4 Adjuvant analgesics

Drug class	Daily adult starting dose[a] (range)	Routes of administration	Adverse effects	Indications
Antidepressants	Nortriptyline 10–25 mg	PO	Anticholinergic effects	Neuropathic pain
	Desipramine 10–25 mg	PO		
	Venlafaxine 37.5 mg bid	PO	Nausea, dizziness	
	Duloxetine 30 mg	PO	Nausea	
Anticonvulsants	Clonazepam 0.5–1 mg HS, bid or tid	PO	Sedation	Neuropathic pain
	Carbamazepine 100 mg qday or tid	PO	Sedation, Aplastic anemia (rare)	
	Gabapentin 100–300 mg tid	PO	Sedation, dizziness	
	Pregabalin 50 mg bid or tid		Sedation, dizziness	
Corticosteroids	Dexamethasone 2–24 mg qday; may give up to 100 mg IV bolus for pain crises	PO/IV/SQ	"Steroid psychosis," dyspepsia	Cerebral edema, spinal cord compression, bone pain, neuropathic pain, visceral pain
	Prednisone 15–30 mg tid	PO		
Local anesthetics	Lidocaine 1–5 mg/kg hourly	IV or SQ infusion	Lightheadedness, arrhythmias	Neuropathic pain
N-Methyl-D-aspartate antagonists	Dextromethorphan, effective dose unknown	PO	Confusion	Neuropathic pain
	Ketamine (see Pain Crises)	IV		
Calcitonin	25 IU/day	SQ/nasal	Hypersensitivity reaction, nausea	Neuropathic pain, bone pain
Capsaicin	0.025–0.075% cream 8% patch	Topical	Burning	Neuropathic pain
Baclofen	10 mg qday or tid	PO	Muscle weakness, cognitive changes	
Calcium channel blockers	Nifedipine 10 mg tid	PO	Bradycardia, hypotension	Ischemic pain, neuropathic pain, smooth muscle spasms with pain

[a] Pediatric doses for pain control not well established.

Source: References 9, 40.

stick and other minor procedures. Both gel and patch versions of lidocaine have been shown to reduce the pain of postherpetic neuropathy. Intravenous or subcutaneous lidocaine at 1–5 mg/kg (maximum 500 mg) administered over 1 hour, followed by a continuous infusion of 1–2 mg/kg/hr has been reported to reduce intractable neuropathic pain in patients in inpatient palliative care and home hospice settings in adults and children.[102–104]

N-Methyl-D-Aspartate Antagonists: Ketamine

Antagonists to NMDA are believed to block the binding of excitatory amino acids, such as glutamate, in the spinal cord. Ketamine, a dissociative anesthetic, is believed to relieve severe neuropathic pain by blocking NMDA receptors. Case reports and small studies suggest that intravenous or oral ketamine can be used in adults and children for their relief of neuropathic pain or to reduce opioid doses.[105] A Cochrane review found insufficient trials conducted to determine safety and efficacy when used in combination with morphine in cancer pain.[106] However, a systematic review concluded that although limitations in the data exist, ketamine may be an option for refractory cancer pain.[107]

Ketamine is commercially available in the United States only in a parenteral formulation. If the oral route is indicated, a palatable solution can be compounded or the parenteral solution ingested, usually mixed with juice or other liquids to mask the bitter taste. Because the opioid-sparing effect is so pronounced, the opioid dose should be reduced by 25–50% when initiating ketamine (Box 9.3). Routine use often is limited by cognitive changes, hallucinations, and other adverse effects, although small studies suggest that gradual upward titration may prevent these effects in adults and children.[108,109] Topical ketamine, usually in combination with amitriptyline and baclofen, may be useful for neuropathic conditions due to cancer treatment such as chemotherapy-induced peripheral neuropathy.[110] More research is needed regarding the efficacy of and adverse effects associated with the use of ketamine for intractable pain in the palliative care population.

Bisphosphonates

Bisphosphonates, such as pamidronate, zoledronic acid, and ibandronate, inhibit osteoclast-mediated bone resorption.

Bisphosphonates treat hypercalcemia and prevent pain related to skeletal events such as metastatic bone disease and multiple myeloma.[111] Denosumab, a RANKL inhibitor, prevents the development of osteoclasts and has been shown to reduce skeletal related events associated with solid tumors, which would reduce pain associated with fractures. A recent review questions the analgesic efficacy of these agents and concludes that bisphosphonates and denosumab appear to be beneficial in preventing pain by delaying the onset of skeletal events.[112] A Cochrane review of these agents used to treat bone metastases of breast cancer found some evidence to support pain relief,[111] yet a review of their use in prostate cancer found no benefit in reducing pain.[113] Toxicities include renal dysfunction and osteonecrosis of the jaw. Clodronate and sodium etidronate appear to provide little or no analgesia.

Calcitonin

Subcutaneous calcitonin may be effective in the relief of bone pain, although studies are inconclusive.[114] The nasal form of this drug may be more acceptable in end-of-life care when other therapies are ineffective. Usual doses are 100–200 IU/day subcutaneously or nasally.

Radiation Therapy and Radiopharmaceuticals

Radiotherapy can be enormously beneficial in relieving pain due to bone metastases or other lesions.[115] In many cases, single-fraction external beam therapy can be used to facilitate treatment in debilitated patients.[116] Goals of treatment should be clearly articulated, so that patients and family members understand the role of this therapy. Targeted therapies, also referred to as cyberknife or gamma knife radiosurgery, can be effective in selected situations.[117] Radiolabeled agents, also described as radiopharmaceuticals, such as strontium-89 and samarium-153, have been shown to be effective at reducing metastatic bone pain.[118] Thrombocytopenia and leukopenia are relative contraindications since strontium-89 can cause thrombocytopenia in as many as 33% of those treated and leukopenia in up to 10%. Because of the delayed onset and timing of peak effect, only those patients with a projected life span of greater than 3 months should be considered for treatment. Patients should be advised that a transitory pain flare can occur after either external beam therapy or radiolabeled agents; additional analgesics should be provided in anticipation.

Chemotherapy

Palliative chemotherapy is the use of antitumor therapy to relieve symptoms associated with malignancy. Patient goals, performance status, sensitivity of the tumor, and potential toxicities must be considered. Examples of symptoms that may improve with chemotherapy include hormonal therapy in breast cancer to relieve chest wall pain due to tumor ulceration, or chemotherapy in lung cancer to relieve dyspnea. However, in a study of patients with stage IV cancers, 69% of those with lung and 81% of those with colorectal cancers did not understand the chemotherapy was not curative.[119] A prospective trial of palliative chemotherapy given 4 months before death revealed an increased risk of undergoing cardiopulmonary resuscitation, mechanical ventilation, or dying in an intensive care unit.[120] Clear discussions regarding the goals of therapy are warranted.

Other Adjunct Analgesics

Topical *capsaicin* is believed to relieve pain by inhibiting the release of substance P. This compound has been shown to be useful in relieving pain associated with post-mastectomy syndrome, postherpetic neuralgia, and postsurgical neuropathic pain in cancer. A burning sensation experienced by patients is a common reason for discontinuing therapy. A Cochrane review of low-dose topical capsaicin found this therapy unlikely to have meaningful effect, but that the high concentration (8%) topical capsaicin patch has been found to be effective in treating HIV-associated and other painful neuropathies.[121]

Patients often ask about *cannabinoids* for the relief of pain particularly as many states have legalized medical marijuana. Major advances, such as the characterization of the cannabinoid receptors (CB1 and CB2), have increased our understanding of the role of these receptors in pain.[122] Review of existing literature evaluating the role of cannabinoids supports some benefit for relief of neuropathic pain with adverse effects that include short-term cognitive impairment.[123,124] Questions regarding the long-term safety and regulatory implications remain.[125] Of importance to prescribers is that although a state may have legalized marijuana, its possession, sale, and use remain a federal offense. The greater insight into cannabinoid receptors has allowed the development of more selective agents that might provide analgesia without the central nervous system depressant effects seen with tetrahydrocannabinol (THC). Nabiximols, an oral cannabinoid spray shown to be effective in advanced cancer pain poorly responsive to opioids, has been approved in Canada and several countries in Europe for the relief of neuropathic pain.[126,127]

Baclofen is useful in the relief of spasm-associated pain. Doses usually begin at 10 mg/day, increasing every few days. A generalized feeling of weakness and confusion or hallucinations often occurs with doses above 60 mg/day. A small retrospective chart review of patients with neuropathic cancer pain suggested benefit from oral baclofen.[128]

Dexmedetomidine is an alpha-2 adrenergic agonist used primarily within intensive care or during invasive procedures. Early case reports suggest it may provide relief in intractable pain, although cost and hypotension may limit its use.[129]

Interventional Therapies

In addition to previously discussed spinal administration of analgesics, interventional therapies to relieve pain at end of life can be beneficial, including nerve blocks, vertebroplasty, kyphoplasty, radiofrequency or cryoablation of painful metastases, procedures to drain painful effusions, and other techniques.[130–132] Few of these procedures have undergone controlled clinical studies. One technique, the celiac plexus block, has been shown to be superior to morphine alone in patients with pain due to unresectable pancreatic cancer, although persistent diarrhea is a potential risk.[133,134] *Botulinum toxin* (sometimes referred to as Botox) can be injected into areas of muscle spasticity, with reductions in tightness and pain. This has been used extensively in migraine treatment and chronic pain conditions and has been found to be of benefit in peripheral neuropathic pain.[135,136]

A complete review of interventional procedures can be found in a variety of sources. The choice of one of these techniques depends on the availability of experts in this area who understand the special

Box 9.3 Palliative Care Program Guideline: Ketamine Utilization for Palliative Care

This is a guideline only. Due to patient variability and nuance, clinical decisions may deviate from this document.

Purpose: Ketamine is an adjunct medication often considered for opioid-refractory pain or intractable side effects from opioids, particularly if the pain is neuropathic in nature or if a high degree of morphine tolerance is suspected.

Definition: Ketamine is an N-methyl-D-aspartate receptor (NMDA) agent which may be opioid sparing.

Consultation and recommendations by the Pain Service and/or Palliative Care Service are required to ensure that all other pain management measures have been considered and for guidance in the process.

Protocol:

A. Oral Dosing

1. The typical starting dose is 10–15 mg orally every 6 hours. Reversal of morphine tolerance may occur at low doses such as this, while management of neuropathic pain is likely to require higher doses.
    a. There is no commercially available oral product. The injectable product may be diluted from its standard concentration of 50 mg/mL or 100 mg/mL with cherry syrup or cola to mask the bitter taste when given orally.
    b. Consider decreasing long-acting opioid by 25–50%.
2. Dosing may be increased daily by 10 mg every 6 hours until pain is relieved or side effects occur. Do not increase doses more frequently than every 24 hours.
    a. Major side effects include dizziness, a dream-like feeling, and auditory or visual hallucinations. If intolerable side effects occur, ketamine should be decreased to the previous dose or discontinued. Resolution may not occur for 24 hours.
    b. Oral doses as high as 1,000 mg/day have been reported in the neuropathic pain literature with average oral doses of 200 mg/day in divided doses required for pain relief.

B. Parenteral Dosing (palliative care provider will be present for initial dose)

1. Ketamine may be given intravenously or subcutaneously if the oral route is not available. A trial bolus of 5–10 mg IV can also be considered, which may be repeated once after 15–30 minutes.
    a. The starting infusion dose is 2–3 mcg/kg/min, which may then be increased by 1 mcg/kg/min every 1 hour up to a maximum of 6 mcg/kg/min.
    b. Consider decreasing long-acting opioid by 25–50%.
    c. The injectable solution is irritating and may require the subcutaneous needle to be changed daily.

- In case of adverse psychiatric reaction, have haloperidol 1 mg every 10 minutes as needed available; may increase as needed to achieve control.

Source: Palliative Care Program, Medical University of South Carolina, Charleston, SC; with permission.

needs of palliative care patients, the patient's ability to undergo the procedure, and the patient's and family's goals of care.

Nonpharmacological Therapies

Nondrug therapies, including cognitive–behavioral techniques and physical measures, can serve as adjuncts to analgesics in the palliative care setting. This is not to suggest that when these therapies work, the pain is of psychological origin. The patient's and caregivers' abilities to participate must be considered when selecting one of these therapies, including their fatigue level, interest, cognitive level, and other factors.[137,138]

Cognitive–behavioral therapy often includes strategies to improve coping and relaxation, such as relaxation, guided imagery, music, prayer, and reframing.[139] These strategies have been found to be useful in reducing pain and anxiety and improving sleep in those with advanced disease as well as reducing endocrine symptoms in women being treated for breast cancer. Physical measures such as massage, reflexology, heat, chiropractic, and other techniques have also been shown to produce relaxation and relieve pain.[140]

Integrative therapies include acupuncture, aromatherapy, herbal therapies, and many other techniques formerly called *complementary and integrative therapies*. See Chapter 28 for information about these approaches to pain and symptom management. More rigorous research is needed in the palliative care setting regarding all of the nondrug therapies that might enhance pain relief.

Principles of Pain Management

Pain is a biopsychosocial and spiritual phenomenon, and this is particularly true in those with life-threatening illnesses. Therefore, multimodal therapies, incorporating pharmacologic, nonpharmacologic, and integrative therapies, are indicated for the relief of pain in this population. When applied carefully, these treatments provide relief for the majority of patients (Box 9.4).

Pain Crisis and Refractory Pain at the End of Life

Most pain seen in palliative care is controllable with appropriate use of pharmacologic, nonpharmacologic, and integrative therapies. Some neuropathic pains, such as invasive and compressive neuropathies, plexopathies, and myelopathies, may be poorly responsive to conventional analgesic therapies short of inducing a nearly comatose state. Widespread bone metastases or end-stage pathological fractures may present similar challenges. When confronted by a pain crisis, the following considerations will be helpful:

- Differentiate terminal agitation or anxiety from "physically" based pain, if possible. Terminal symptoms unresponsive to rapid upward titration of an opioid may respond to benzodiazepines (e.g., lorazepam, midazolam).
- Make sure that drugs are getting absorbed. The only route guaranteed to be absorbed is the intravenous route. Although invasive routes of drug delivery are to be avoided unless necessary, if there is any question about oral, enteral, or transdermal absorption of analgesics or other necessary palliative drugs, parenteral access should be established.
- Preterminal pain crises that respond poorly to basic approaches to analgesic therapy merit consultation with a pain management consultant as quickly as possible. Radiotherapeutic, anesthetic, or neuroablative procedures may be indicated.

Box 9.4 Guidelines for Pain Management in Palliative Care

- Sustained-release formulations and around-the-clock dosing should be used for continuous pain syndromes.
- Immediate-release formulations should be made available for breakthrough pain. Each breakthrough dose is usually 10–20% of the 24-hour dose of the sustained-release formulation. Thus, as the sustained-release dose increases, so does the immediate-release dose.
- Cost, convenience, and availability of medications (and other identified issues influencing compliance) are highly practical and important matters that should be taken into account with every prescription.
- Anticipate, prevent, and treat predictable side effects and adverse drug effects.
- Titrate analgesics based on patient goals, requirements for supplemental analgesics, pain intensity, severity of undesirable or adverse drug effects, measures of functionality, sleep, emotional state, and patients'/caregivers' reports of impact of pain on quality of life.
- Monitor patient status frequently during dose titration.
- Be aware of potential drug–drug and drug–disease interactions.
- Incorporate nonpharmacologic and integrative therapies.
- Recommend expert pain management and/or palliative care specialty consultation if pain is not adequately relieved within a reasonable amount of time after applying standard analgesic guidelines and interventions.
- Know the qualifications, experience, skills, and availability of pain management experts (consultants) within the patient's community before they may be needed.

These basic guidelines and considerations will optimize the pharmacologic management of all patients with pain, particularly those in the palliative care setting.[9,40]

Management of Refractory Symptoms at the End of Life

Sedation at the end of life is an important option for patients at home or in the hospital with intractable pain, delirium, dyspnea, or other symptoms. The most commonly employed agents include benzodiazepines, including midazolam or lorazepam, barbiturates, and in some cases, propofol.[141] Palliative sedation is best delivered under the guidance of experts in palliative care and is usually reserved for those patients who are expected to die within hours to days.[142] Light sedation may first be attempted to allow communication with loved ones, although in some circumstances this may be insufficient to relieve the intractable symptoms. In a survey of loved ones of patients who had died, some having received sedation while others had not, the use of sedation had no negative effect on the relatives' perception of the quality of dying or of their own well-being.[143] See Chapter 27 for extensive discussion regarding palliative sedation.

Pain Control in People with Substance Abuse Disorders

The numbers of patients entering palliative care with a current or past history of substance abuse disorders are unknown yet thought to be significant and increasing in concert with the exploding opioid misuse epidemic. The use of universal precautions and risk mitigation strategies is essential when assessing all individuals in pain to reduce risk associated with the use of opioids and other controlled substances.[144] Important principles and practical considerations guide the care of those individuals with previous or current substance use disorder who require treatment of pain in the palliative care setting (see Chapter 42 for a complete discussion of care for the addicted patient at the end of life).

Case Study

Sylvia Johnson was a 45-year-old woman with metastatic colorectal cancer. She had been receiving chemotherapy with the goal to reduce tumor burden and relieve symptoms, including pain, yet she now had extension of the tumor into the pelvis, along with liver metastases. She lived alone but had family support in the community and she continued to work throughout the course of treatment. Her goal was to continue chemotherapy, have the ostomy reversed, and work full-time; she strongly declined any conversations regarding prognosis. She reported severe throbbing and burning pain in the rectal region with radiation down the left leg; she was taking hydrocodone/acetaminophen 10/325 mg 2 tablets every 3 hours without adequate relief. Because of the frequent requests for refills, the oncology team was concerned about misuse of the drug and consulted palliative care.

The palliative care team conducted a thorough pain assessment and screened for risk for opioid misuse. She had no obvious risk factors. Due to concerns regarding acetaminophen intake, the team added morphine extended-release 60 mg every 12 hours and continued hydrocodone/acetaminophen 10/325 mg 1 tablet every 3 hours as needed. She was also started on gabapentin for the neuropathic component of pain. She was educated about safe use and storage of the medication.

After a few weeks of treatment with this regimen, the team was contacted by a physician from an outside hospital; Ms. Johnson was in the ICU with a hemoglobin of 5.4 gm/dL (normal 11.6–15.4 mg/dL) and a creatinine 6.0 mg/dL (normal 0.51–7.17 mg/dL). Apparently she had been supplementing the analgesic regimen with large doses of OTC NSAIDs and acetaminophen and developed a gastrointestinal bleed along with acute kidney and hepatic injury. Several transfusions of packed red blood cells and fluid resuscitation, along with clipping of the ulcer under upper GI endoscopy, helped restore normal values. She was switched to fentanyl patch 50 mcg and oxycodone immediate-release 15 mg prior to discharge; gabapentin was held until complete resolution of kidney and hepatic injury.

Despite aggressive therapy, the disease advanced along with pain, anxiety, and sleep disorders. The fentanyl patch was gradually titrated to 100 mcg every 48 hours, as she reported increased pain on day 3 of application. She was using oxycodone immediate release 30 mg, 1–2 tablets every 3 hours for breakthrough pain, and the gabapentin had been restarted and titrated to 900 mg three times a day. Clonazepam was added at night and in reduced doses during the daytime to address anxiety. There was an episode when she requested a refill of oxycodone early; review of the state prescription drug monitoring program data revealed that she received only 40 tablets at the last refill, although 150 tablets had been ordered. A call to the pharmacy revealed they had only a limited supply and had to provide a partial fill.

Although initially reluctant to discuss advance directives or goals, she now began to accept and seek support, including hospice care. Her family provided support to allow her to remain at home, and she died comfortably with limited pain or symptom burden.

Ms. Johnson's case illustrates several important points about pain management in palliative care, particularly highlighting the need for assessment as the patient's condition changes over time. Other key concepts:

- Evaluate acetaminophen and NSAID intake when using combination products; this can be exacerbated by use of OTC agents. Serious adverse effects can occur.
- Neuropathic pain requires multimodal therapy, including adjuvant analgesics.
- Use of alternate routes of drug delivery is common at end of life; use equianalgesic principles when converting from one opioid to another or from one route to another.
- Frequent requests for refills do not always indicate issues related to misuse; inadequate numbers of pills may be ordered, and, at times, pharmacies may partially fill a prescription due to drug shortages. Further investigation is warranted. Screening for risk factors associated with substance abuse is crucial for all patients so these issues can be adequately addressed.
- Patients and caregivers need to understand that opioids are not to be used to treat sleep, anxiety, or mood disorders. Although use of opioids may initially be sedating, tolerance will develop and high doses will be needed to obtain the original effect. Careful assessment is needed, and appropriate pharmacologic and nonpharmacologic therapies of these comorbid conditions (sleep, anxiety, and sadness/depression) are necessary.
- Safe storage principles of controlled substances should be taught and implemented in the home.

Conclusion

Pain control in the palliative care setting is feasible in the majority of patients. Understanding the barriers that limit relief will lead to improved education and other strategies to address these obstacles. Ongoing, skilled assessment captures changes in pain and other symptoms as the patient's condition evolves. Developing comfort and skill with the use of pharmacological and nonpharmacological therapies will enhance pain relief. Together, these efforts will reduce suffering, relieve pain, and enhance the quality of life of those at the end of life.

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CHAPTER 10

Fatigue

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Key Points

- Fatigue is the most common chronic symptom associated with cancer and other chronic progressive diseases.
- Thorough assessment of all patient comorbidities and symptoms is critical to accurately diagnose and treat disease-related fatigue.
- Education interventions in fatigue directed at healthcare providers, patients, and families provide an important opportunity for consistent integration of current guidelines into practice.
- Ongoing research has provided lines of evidence for improved patient outcomes through both pharmacological and nonpharmacological measures.

Introduction

Fatigue is identified as a "common phenomenon in modern society" yet has no widely accepted definition and affects populations differently.[1–4] Commonly, it is a symptom exhibited following a stressor, activity, disease, and or treatment. Fatigue can be a natural and healthy defense against physical or emotional stress, where symptoms are largely relieved following natural rest. However, in the presence of neoplastic and chronic disease, fatigue is typically not relieved by rest and consequently has a detrimental impact on quality of life (QOL) for patients and their families, thus presenting a significant management challenge for healthcare providers.[4–6]

Cancer-related fatigue (CRF) is one of the most common, devastating, and multidimensional symptoms associated with cancer diagnosis and treatment.[3,2] Fatigue associated with disease commonly occurs with groups of debilitating symptoms or side effects such as nausea, vomiting, and/or diarrhea. These symptoms occurring together are often referred to as *symptom clusters*.[7] They may vary with diagnosis, stage, and/or treatment severity. The resultant fatigue involves the entire person, touching every facet of daily life. It can progressively interfere with common, daily physical and/or social activity with varying impact on QOL and emotional stability.[1,6] Fatigue may have the greatest potential to interfere with quality at the end of life.[8,9]

Chronically ill patients often do not have the energy or forethought to communicate to healthcare professionals about what may be perceived as a nonurgent symptom.[3] Some may find it difficult to convey the extent of their exhaustion to healthcare providers as a result of lack of understanding and a general acceptance of the disease process, treatment, and side effects. Healthcare providers and other professional staff may consider the stress of fatigue or other symptoms as "expected side effects" of disease and treatment and acknowledge symptoms through "normalization" or acceptance. As such, the psychosocial-emotional impact of fatigue or other symptoms such as loss of appetite and the inability to maintain adequate nutrition and hydration may have significant financial and psychosocial impacts on family interactions as well as on clinical issues and inability to maintain clinical treatment plans.[10]

Definitions of Fatigue

Fatigue is a complex phenomenon, one studied by many disciplines, yet it has no widely accepted definition.[3] Even within different nursing specialties there has been little agreement on a definition of fatigue. CRF is "primarily a subjective, complex whole body experience"[4] and is described as a lack of energy or exhaustion that interferes with normal activities and function.[10]

Fatigue is commonly associated with cancer but is not a stranger to other chronic and accelerating disease processes such as chronic obstructive pulmonary disease (COPD),[11] irreversible cardiomyopathies,[12] chronic renal failure,[13,14] HIV/AIDS,[15] and multiple sclerosis.[16,17] The manifestation of fatigue in any disease process may differ with each diagnosis and treatment. In oncology, for example, patients may perceive fatigue differently depending on when fatigue occurs in the disease trajectory.[1] Often, it is the recognition of fatigue symptoms that initiates pursuit of diagnosis or disease discovery and implementation of medical treatment.[1] Once diagnosed, the cancer patient may experience fatigue as a side effect of treatment, as well as the emotional consequence of a critical disease. The presence of fatigue across various stages of the disease process as a pervasive side effect of treatment often continues well into recovery.[10]

Fatigue is consistently noted to be one of the most prevalent, severe, and distressing symptoms of malignancy and other chronic diseases.[18] Descriptors of fatigue range from a single focus of tiredness to the broad, multifocal, and overwhelming multidimensional syndrome of exhaustion that differs from the anticipated feelings of tiredness that are often felt in healthy individuals and are relieved by adequate rest.[19]

In recovery from disease treatment, the level of energy that returns is commonly less than expected; this is referred to as a "new normal" and then becomes reality.[1] Fatigue is often perceived differently by those living the experience of disease, treatment, and recovery from those who observe the process, including healthcare providers and family. This difference in perception may continue to be observed differently throughout the course of disease or treatment.

Fatigue is often identified by patients as experiential, with descriptors such as "I feel as if I have been run over by a truck." Or, "I can't believe this is me." Differentiating the sensation of fatigue from "tiredness or sleepiness" and assessing its impact on daily life and the patient's ability to function is often difficult for patients but also challenging for healthcare providers, friends, and family.[20,21] In cancer recurrence, fatigue becomes as much an enemy as the diagnosis. As the disease progresses to advanced stages, there is a resultant loss of dignity associated with demoralization and existential distress.[22] Fatigue at the end of life may be experienced as the end of a very long struggle, a natural stage of the dying process, and it may protect against elements of suffering.[22]

The National Comprehensive Cancer Network (NCCN)[3] Fatigue Practice Guidelines Panel, charged with synthesizing research on fatigue to develop recommendations for care, defines fatigue as "a distressing, persistent, and subjective sense of physical, emotional, cognitive tiredness, or exhaustion related to cancer or cancer treatment, that is not proportional to recent activity and interferes with usual functioning."[3]

The American Cancer Society defines CRF as "feeling tired—physically, mentally, and emotionally" and "having less energy to do the things you normally do or want to do."[23] This definition is similar to that used by multiple sclerosis patients, who defined fatigue as one of the most frequent and most disabling symptoms—a subjective lack of physical and/or mental energy that interferes with usual and desired activities.[24,25] Sufferers of other nonmalignant diseases such as stroke and end-stage heart failure define fatigue as being "physically tired and mentally exhausted" and perceive it as one of their worst symptoms, yet one that often receives little attention.[26]

While other definitions have been proposed, two key elements are dominant in most definitions of fatigue: (1) a subjective perception with physical, emotional, and cognitive features and (2) interference with an ability to function, often negatively impacting QOL.[6]

Prevalence

Fatigue is currently reported to be the most common symptom linked to the clinical course of cancer and other chronic diseases.[2,3] Estimates of prevalence are between 50% and 90% depending on the diagnostic category, length of disease, course of treatment, complications, physical state, and a myriad of psychosocial factors.[17,18] Despite the significant prevalence of disabling and distressing symptoms, fatigue remains underdiagnosed and undermanaged. Fatigue has been indicated as the most prevalent, disabling, and continuous phenomenon in patients receiving various treatments for cancer.[10] Fatigue cuts across all diagnoses, ages, genders, stages of disease, and treatment modalities.[8] Both chemotherapy and radiation therapy result in fatigue, while fatigue following combined chemoradiation therapy continues to be underestimated and profoundly affects QOL. Furthermore, "fatigue may persist for months or years" following curative treatment.[27,28]

Cancer is only one of many diseases in which fatigue is a common symptom. Prevalence rates for CRF and other chronic diseases are identified in Box 10.1, including cardiac disease,[9] COPD,[11] renal disease,[14] HIV/AIDS,[15,29] and multiple sclerosis.[16]

While symptoms rarely occur in isolation, there is growing evidence to support the occurrence of multiple symptom "clusters" along with the concept of symptom burden.[7,30] The increase in symptom cluster conditions is expanding. For example, when cancer was a comorbid condition in rheumatoid arthritis, 60% of subjects reported fatigue.[31] Other studies suggest a correlation between fatigue, physical function, systemic inflammatory response, and psychological distress in advanced cancer.[28]

Box 10.1 Prevalence of Fatigue and Populations at Risk

Cancer

Prevalence rates of cancer-related fatigue (CRF) vary depending on cancer type and stage, as well as the diagnostic criteria. One study indicated that more than 80% of patients receiving radiotherapy experience fatigue, as did up to 90% of incurable cancer patients. Fatigue is also the most common and distressing symptom experienced by pediatric cancer patients. In some cancer survivors, fatigue persists months or even years after treatment.[1,3,19]

Cardiac

Research suggests the widespread presence of fatigue in patients with chronic heart failure. One such study of these patients indicated that 99% of the sample reported fatigue.[9]

Chronic Obstructive Pulmonary Disease

Second only to breathlessness in its prevalence, fatigue is experienced by 96% of those with COPD.[11]

Renal Disease

In renal disease, the prevalence of fatigue varies depending on the method of treatment employed. Of those treated by hemodialysis, 82% report fatigue, notably physical fatigue and reduced activity. Fatigue prevalence in those treated by peritoneal dialysis was greater than 88%.[14]

HIV/AIDS

The diagnosis of HIV/AIDS is now more consistently addressed as a chronic disease rather than as a terminal illness as a result of antiviral therapy. However, as the disease becomes more chronic, fatigue is now recognized as an ongoing, chronic symptom and needs to be recognized and treated as such.[15,29]

The prevalence of fatigue in HIV-positive patients, according to one study, was 69%. While fatigue was not the most common symptom in AIDS patients, it was nonetheless widespread, affecting at least 42% of patients.

Multiple Sclerosis

Fatigue is the most prevalent and potentially debilitating symptom of multiple sclerosis. It is experienced by 75–95% of multiple sclerosis patients, more than half of whom name fatigue as one of their most distressing symptoms. Much of the treatment for multiple sclerosis–related fatigue involves eliminating secondary causes of fatigue (depression, sleep problems, medications) and using energy more efficiently. The FDA has not approved any drugs to specifically treat multiple sclerosis; however, medications such as amantadine, modafinil, or methylphenidate are sometimes used.[16,25]

Pathophysiology

Causes of fatigue are associated with multifactorial issues including anemia, chemotherapy or other related treatments, and comorbid symptoms such as pain, depression, and anxiety.[27] Anemia can result in severe fatigue and significantly impair QOL. It has a profound impact on patients, with additional complications that include dyspnea, palpitations, dizziness, and decreased cognitive function.[32] These symptoms can be common in patients with advanced disease or who are receiving aggressive therapy. Use of hematopoietic growth factors or erythropoietin-stimulating agents (ESAs) are known to relieve symptomatology and have been utilized to alleviate some degree of fatigue. However, recent research clearly indicates an increased risk of thromboembolic events with use of ESAs.[32,33]

Some evidence suggests that dysregulation of pro-inflammatory cytokines may play a mechanistic role in the symptom of fatigue as a common biological mechanism.[23] Pro-inflammatory cytokines may be released as part of the host response to infection, tumor, tissue damage from injury, or depletion of immune cells associated with treatments. These inflammatory stimuli can signal the central nervous system to generate fatigue as well as changes in sleep, appetite, reproduction, and social behavior.[4,34,35]

Fatigue, like pain, is not only explained by physiological mechanisms, but must be understood as a multicausal, multidimensional phenomenon that includes physical, psychological, social, and spiritual aspects.[19,34,36]

Factors Influencing Fatigue

Many characteristics that may predispose patients with other advanced diseases to develop similar fatigue syndromes have not been studied comprehensively. However, the increase of fatigue prevalence has stimulated oncology research to identify and quantify patient characteristics in treatment-related fatigue for clinical identification and development of treatment modalities.[37] Box 10.2 provides a list of factors that have been identified.

Box 10.2 Risk Factors Associated with Fatigue

Personal Factors

- Age
- Marital status
- Menopausal status
- Income/insurance

Psychosocial Factors

- Mental and emotional state (depression, fear, anxiety, distress, conflicts)
- Culture/ethnicity
- Living situation

Care-Related Factors

- Number/cohesiveness of caregivers
- Responsiveness of healthcare providers

Disease-Related Factors

- Stage and extent of disease
- Comorbidities
- Anemia
- Pain
- Dyspnea
- Nutritional changes (weight loss, cachexia, and electrolyte imbalance)
- Continence
- Sleep patterns/interruptions

Treatment-Related Factors

- Any treatment-related effect from surgery, chemotherapy, or radiation (skin reaction, temporary altered energy level, urinary/bowel changes, pain)
- Medication issues (side effects, polypharmacy, taste changes, over-the-counter medications)
- Permanent physiological changes

Patients with cancer, when compared with others with nonmalignant disease, express more fatigue, have worse sleep quality, more disrupted circadian rhythms, worse QOL, and lower activity levels.[38] The more advanced the cancer, the greater the occurrence of fatigue.[38]

The most frequent and problematic issue following an acute myocardial infarction is fatigue, which is often expressed in the same terminology used by those experiencing CRF.[26] Symptoms are similar in that they are poorly defined and often underidentified. Many of the experiences parallel that of patients with malignancy. Participants in one study identified interference with daily functional status and described symptoms related to depression.[39,40]

Similarly, patients with end-stage renal disease on chronic dialysis complain of high levels of pain and fatigue associated with other symptoms. Other associated symptoms, headaches, cramps, itching, dyspnea, nausea and vomiting, and sleep disruption often identify severe fatigue and symptom distress as significant.[14]

In one study, 100 patients with rheumatoid arthritis (RA) were asked to identify factors that contributed to their fatigue. Results indicated that the rheumatoid disease process itself was the primary cause of fatigue; joint pain was specifically mentioned.[31] Disturbed sleep was the second most frequent factor, and physical effort to accomplish daily tasks ranked third.[31] Patients with RA indicated that they had to exert twice the effort and energy to accomplish the same amount of work. In another study, women with RA reported more fatigue than men; the authors explained this variance as a result of female patients' higher degrees of pain and poor quality of sleep.[41]

Many characteristics that may predispose patients with other advanced diseases to develop similar fatigue syndromes have not been studied comprehensively. However, depression and fatigue are two related concepts often linked to cancer patients.[42] Fatigue is part of the diagnostic criteria for depression, and depression may develop as a result of being fatigued. While depression is reported less frequently, feelings of depression are common in patients with cancer. Research indicates that women who are fatigued score twice as high on the depression scale as those who were not fatigued and that depression is the strongest predictor of fatigue.[42]

Depression and fatigue may coexist with cancer without having a causal relationship since each can originate from the same pathology.[42] Fatigue in patients undergoing cancer treatment has been closely linked with other distressing symptoms, such as pain, dyspnea, anorexia, constipation, sleep disruption, depression, anxiety, and other mood states impacting patient QOL.[42]

Rather than focusing on specific individual symptoms, an earlier, more consistent, and thorough nursing assessment allows the identification in patients of symptom clusters associated with disease related fatigue.[43] Early recognition and intervention and management may improve patient outcomes. As CRF may be apparent before, during, and after treatment, nursing practice is called to continue the exploration of symptom relationships and identify opportunities for interdisciplinary collaboration to improve support for vulnerable populations.[44,45]

Assessment of Fatigue

Assessment of the whole person, physical, psychosocial, and emotional, of the mind and spirit as well as the body, is as essential in the recognition of fatigue as it is in pain. Fatigue, like pain, is also a subjective interpretation of various stimuli determined by the person who is experiencing the sensation. Caregiver or staff perceptions may differ from those articulated by the person experiencing fatigue.

The NCCN guidelines[3] for CRF clearly delineate steps and processes to put the assessment and recognition of fatigue on the same level as pain and calls for caregivers "to screen every patient for fatigue as a vital sign at regular intervals" using an age-related severity scale and, based on those findings, to implement a program of patient education and strategies to manage fatigue.[3] The guidelines also include a step-by-step diagram from a "focused history" to specific interventions of nonpharmacological and pharmacological treatment, from the evaluation phase through active treatment, post treatment, and the end of life.

There are numerous methods of assessing and diagnosing fatigue. Recognizing the importance of CRF, the diagnosis has been proposed for inclusion in the International Classification of Diseases (Box 10.3). However, some researchers suggest that the diagnostic criteria are too stringent, and the strict exclusion of those with possible "mood disorders" is of concern and may underestimate fatigue occurrence.

Box 10.3 Criteria for Diagnosing and Evaluating Fatigue

Criteria for diagnosing and evaluating fatigue include the presence, frequency (sporadic or constant), duration, and degree of interference with activities of daily living (ADLs).

1. Complaints of generalized weakness or limb heaviness
2. Diminished concentration or attention
3. Decreased motivation or interest in engaging in usual activities
4. Insomnia or hypersomnia
5. Sleep is unrefreshing or nonrestorative
6. Perceived need to struggle to overcome inactivity
7. Marked emotional reactivity to feeling fatigued (sadness, frustration, irritability)
8. Difficulty in completing daily tasks attributed to feeling fatigued
9. Perceived problems with short-term memory
10. Postexertional malaise lasting several hours

Fatigue, as with any symptom, is not static. Changes take place daily and sometimes hourly in the patient with an advanced illness. As such, fatigue bears repeated evaluation on the part of the healthcare provider. An example of a thorough assessment of the symptom of fatigue is found in Box 10.3, which uses both a subjective and an objective framework to ascertain patient fatigue and possible underlying physiological events that may exacerbate the fatigue. Important areas to explore are patient and family beliefs and expectations related to the fatigue experience and awareness of changes in energy levels, exacerbation and remission of symptoms, and what improves the level of fatigue.[27]

Many scales have been developed to measure fatigue in the adult with varying levels of validity and reliability. Examples of fatigue measurement tools include the Multidimensional Assessment of Fatigue, the Symptom Distress Scale, the Fatigue Scale, the Fatigue Observation Checklist, and a Visual Analog Scale for Fatigue.[46] These scales are available for use in research and may be used in the clinical arena. A comprehensive review by Piper and colleagues[47] describes the advantages and disadvantages of the single-item as well as multi-item, multidimensional CRF measures currently in use. The European Association for Palliative Care compiled a list of assessment instruments that have been used in research for fatigue in the palliative care group.[48] One scale that has been used extensively in the oncology population is the Piper Fatigue Scale. This questionnaire has 22 items that measure four dimensions of fatigue: affective meaning, behavioral/severity, cognitive/mood, and sensory. This scale measures perception, performance, motivation, and change in physical and mental activities.[49]

As symptoms are identified, caregivers must be aware of the presence of other clinically significant distress or impairment in social, occupational, or other important areas of functioning and report these to the medical team. Other important considerations include evidence from the history, physical examination, or laboratory findings that symptoms are a consequence of disease-directed therapy or determination that symptoms are not primarily a consequence of a comorbid psychiatric disorder (e.g., major depression, somatization disorder, somatoform disorder, or delirium).

The perception of fatigue is most efficiently assessed when a self-report scale is offered to patients, similar to the evaluation of pain. It allows a quantification of patient fatigue using a visual analog scale (VAS) where 0 equals no fatigue and 10 equals severe fatigue that interferes with some function.[6] As with the use of any measurement tool, consistency of utilization over time is essential to understanding the measurement by both patient and professional staff.

Management and Treatment of Fatigue

Fatigue may be identified and treated in the absence of an absolute cause through recognition of contributing factors such as anemia, deconditioning, depression, dehydration, hypoxia, metabolic and endocrine disorders, insomnia, pain, malnutrition, infection, or other comorbidities. Identifiable goals are to alleviate recognizable factors contributing to fatigue in general and provide support systems to develop or improve patients' and families' coping mechanisms. Often the acknowledgment of the potential of fatigue in any chronic disease assists with understanding the phenomena. It is beneficial for family members to understand the potential exhaustion of illness and its treatment. Frequently, patient and family both are under the impression that once treatment is complete, fatigue, like the disease, will "disappear."[19]

When considering palliative care, the management of fatigue is extremely challenging. By its very definition, palliative care may encompass a prolonged period ranging from early in the course of a disease when a person may be physically and socially active to a few weeks before death, when all activity may diminish considerably. With fatigue interventions, the wishes of the patient and family are paramount. Effective management takes into consideration the extent of the disease, other symptoms, whether or not palliative treatment is still in process, and the age, developmental and emotional status, and the physical location of the patient.[49] Intervention and treatment for fatigue are suggested to occur at two levels: management of symptoms that contribute to fatigue and prevention of additional or secondary fatigue by maintaining a balance between restorative rest and restorative activity. Fatigue interventions have been grouped into two broad categories: pharmacological and nonpharmacological related to associated causes and symptoms. Treatment may include both of these modalities and may be adjusted to meet the changes in status.

Pharmacological and Herbal Interventions

Pharmacological approaches to treat fatigue in patients with cancer and chronic progressive diseases include both Food and Drug Administration (FDA)-approved medications and herbal therapies. More frequently used pharmacological therapies include corticosteroids and psychostimulants and, to a lesser degree, antidepressants, tumor necrosis factor alpha, micronutrients, and various other classes of drugs. Corticosteroids such as dexamethasone are commonly used to counteract fatigue, poor appetite, and nausea.[50] However, side effects may include insomnia, mood swings, elevation of blood glucose, and increased occurrence of *Candida* infection. A large study was conducted with the psychostimulant methylphenidate to identify its effects on depression and cognition associated with CRF.[51] Analysis demonstrated limited evidence to support treatment and did identify some adverse events of vertigo, anxiety, anorexia, and nausea. When compared to modafinil, other research reported improved results using this drug.[52] One study reported the addition of a central nervous system stimulant that might counteract the somnolence of opioid use and, as a result, might enhance the effects of pain medication and increase patient activity levels.[53]

Although treatment results suggest that erythropoietin reduces the need for red blood cell transfusion, it may in fact "increase the risk of thromboembolic events."[32] Other drugs have been used to combat chronic disease-related fatigue. Clinical trials of tumor necrosis factor alpha (etanercept) have had some effects on fatigue for patients experiencing rheumatoid arthritis.[54]

One study reviewed the treatment of fatigue with modafinil to evaluate efficacy and tolerability in non–small cell lung cancer (NSCLC) patients in a treatment versus placebo trial. The results indicated no difference between the two groups and reported that modafinil had no effect on CRF and should not be prescribed outside a clinical trial setting.[55] Another study explored the use of modafinil in hepatitis C and HIV/AIDS patients, in whom it appeared to be effective.[56]

The benefit of herbal therapy was clearly demonstrated with a trial for treatment of CRF with the use of American ginseng 2,000 mg/day with no associated toxicities.[57] Continued exploration with positive results for multiuse pharmaceuticals and alternative medicines are very encouraging for patients with chronic progressive disease and associated fatigue.

Nonpharmacological Interventions

Interventions for fatigue encompass several disciplines. Historically, nurse clinicians and researchers have been the trailblazers in assessing and managing fatigue in the clinical setting. Research has been conducted on all of the fatigue management strategies listed in Table 10.1. Included are patient and staff educational interventions, studies on disrupted sleep patterns, nutritional deficits and their effect on patient QOL, symptom management, and physical and attentional fatigue. Sample sizes have often been small and groups homogeneous, but the studies highlight the contribution of nurse researchers.

Fatigue may demonstrate a response to exercise programs.[27,44] In palliative care, a group exercise program was piloted for those with incurable cancer and a short life expectancy.[58] Outcomes indicated that physical fatigue was reduced. Toward the end of life, the NCCN guidelines recommend general strategies for fatigue management that begin with energy conservation techniques, prioritizing activities, delegating, taking rest periods, and using labor-saving devices. They also recommend optimizing patient activity levels with the consideration of a referral to both physical and occupational therapy. Increased caution was emphasized for those with bone metastases and immunosuppression.

Attentional fatigue has been noted to be disturbing and burdensome to many cancer patients.[59] Many cancer survivors continue to suffer from acute, chronic, and late side effects of treatment, with one of the most onerous side effects being cognitive impairment. Early research indicates that exercise may be an effective intervention for improving the severity of side effects of cognitive impairment, sleep problems, depression, pain, anxiety, and physical dysfunction.

Nutritional consultation for patients has been shown to be key to managing physiological deficiencies from cachexia, nausea, and anorexia. Adequate hydration and the replacement of lost electrolytes enable the fatigue sufferer to have the best opportunity to control fatigue symptoms that are physiologically based.[60]

Sleep disruption is a common problem encountered by patients with advanced chronic progressive disease. Sleep cycles may be negatively affected by innumerable internal and external factors. The disturbances may be actual or perceived, but either results in daytime impairment. Common sleep disturbances resulting in fatigue include insomnia, breathing disorders, and movement disorders.[61] Fatigue interferes with activities of daily living, affects QOL, and may be offered as a reason to discontinue treatment. Sleep disturbances are often reported together with fatigue. One study examined the relationship between fatigue and sleep parameters in women undergoing chemotherapy.[42] The investigators found that fatigue worsened and sleep quality remained poor throughout the course of chemotherapy, although total time of sleep increased over the course of treatment. Additionally, one study of multiple

Table 10.1 Interventions to relieve fatigue

Problem	Intervention	Rationale
Lack of information or lack of preparation	Explain complex nature of fatigue and importance of communication of fatigue level with healthcare providers. Explain causes of fatigue in advanced cancer and chronic progressive diseases and evaluate fatigue level with each visit. ◆ Fatigue can increase in advanced disease. ◆ Cancer cells can compete with body for essential nutrients. ◆ Palliative treatments, infection, and fever increase the body's need for energy. ◆ Anxiety, depression, and tension can contribute to fatigue. ◆ Changes in daily schedules or interrupted sleep schedules contribute to fatigue development. Prepare patient for planned ADL and daily events (eating, moving, visitors, healthcare provider appointments).	Preparatory sensory information reduces anxiety and fatigue. Realistic expectations decrease distress and fatigue.
Disrupted rest/sleep patterns	Evaluate/establish sleep routine: ◆ Usual sleep pattern, length of uninterrupted sleep, temperature in room, activity prior to sleep. ◆ Eating habits prior to sleep, medications, exercise. ◆ Establish/continue regular, routine bedtime and awakening. ◆ Obtain as long sleep sequences as possible, plan uninterrupted time. ◆ Take short rest periods/naps that do not interfere with night sleep. ◆ Use light sources to cue the body into a consistent sleep rhythm. ◆ Pharmacologic management of insomnia should be used when behavioral and cognitive approaches have been exhausted.	Minimizing time in bed helps patients feel refreshed, avoids fragmented sleep, and strengthens circadian rhythm.
Deficient nutritional status	Recommend to patient: ◆ High-protein, nutrient-dense food to "make every mouthful count." ◆ Use protein supplements to augment diet. ◆ Suggest small, frequent meals. ◆ Coordinate time up in chair with meal arrival time. ◆ Socialization may increase oral intake. ◆ Encourage adequate intake of fluids, 8 glasses/day or whatever is tolerated, unless contraindicated. ◆ Consider requesting an appetite stimulant like medroxyprogesterone acetate (Megace).	Increased nutrition will raise energy level. Less energy is needed for digestion with small, frequent meals.
Multi-symptom occurrence	Assess and control symptoms contributing to or coexisting with fatigue such as: pain, sleeplessness, depression, nausea, diarrhea, constipation, electrolyte imbalances, dyspnea, dehydration, infection. Assess for symptoms of anemia and evaluate for the possibility of pharmacologic intervention or transfusion.	Multiple distressing symptoms drain energy and will contribute to marked physical/mental fatigue.
Decreased energy reserves	Plan/schedule activities: ◆ Identify a person to be in charge (fielding questions, answering the phone, organizing meals). ◆ Adjust method/pace of care and move slowly when providing care. ◆ Prioritize and save energy for the most important events. ◆ Eliminate or postpone noncritical activities. ◆ Learn to listen to body; if fatigued, rest. Obtain physical therapy consult: ◆ Mild physical therapy may help joint flexibility and prevent pain. ◆ Engage in individually tailored, team approved exercise/yoga program. Use distraction/restoration: ◆ Encourage activities to restore energy: spending time in natural environment, gardening, listening to music, praying, meditating, engaging in hobbies (art, reading, journaling). ◆ Spend time with family/friends, joining in passive activities (riding in car, watching meal preparation).	Energy conservation helps to reduce fatigue burden and efficiently use energy available. Pleasant activities may reduce/relieve mental (attentional) fatigue.

myeloma patients utilizing a prescribed individualized exercise program revealed significant improvement in fatigue levels.[62]

Psychosocial techniques are the last broad category of fatigue intervention. A meta-analysis of CRF research aimed at evaluating both physical and psychosocial interventions (cognitive-behavioral therapy and counseling) as well as behavioral treatments (massage, yoga) and their effect on fatigue provided evidence that psychosocial interventions, restorative approaches, and counseling therapies have a moderate to strong effect in reducing fatigue.[63]

One of the identified barriers to fatigue management is lack of patient, nursing, and provider knowledge and understanding of the relationship between physical activity and inactivity as it relates to fatigue. Patient, provider, and caregiver education enhances the opportunity for successful fatigue management. Education should include information on such topics as changes in disease status, progression, additional procedure or treatment needs, or medication side effects. Nurse-initiated and -planned educational sessions with the patient and family may provide a forum in which to respond to forgotten questions, reinforce nutritional information, and together manage symptoms to improve QOL.[47]

As the practice guidelines and standards for fatigue management in palliative care continue to evolve, the NCCN fatigue guidelines provide a framework for adults, children, and adolescents suffering from fatigue.[3] It is recommended that quality management be ongoing and implemented as continuous quality improvement projects. Finally, the guidelines suggest that medical care contracts include reimbursement for fatigue-related treatments and that disability insurance address coverage for long-lasting fatigue.[6]

Conclusion

This chapter provides an overview of fatigue as it spans the illness trajectory and end-of-life experience for patients with chronic progressive disease. While fatigue is a complex phenomenon that has been widely studied, it still has no universally accepted definition. Individuals with cancer and many other chronic, progressive diseases continue to experience fatigue, and the costs associated with it—not only in the economic sense but also in its physical, emotional, and psychological impact on life—need to be understood. Many factors, including age, psychological state, social support, access to care, disease type and status, pharmaceutical issues, cognitive impairment, and comorbid conditions influence fatigue. CRF is a serious problem that interferes with physical, psychological, emotional, social, and economic function. The need for healthcare providers to recognize and identify symptoms and explore management strategies is crucial to the lessening of human suffering. Professional nurses are in a unique position to recognize, identify, and explore the needs of patients who may prematurely decline further treatment as a consequence of their fatigue.

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CHAPTER 11

Anorexia and Cachexia

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Key Points

- Anorexia and cachexia are distressing symptoms of advanced and chronic illnesses.
- They are distinct syndromes but clinically difficult to differentiate.
- Metabolic alterations are the primary cause of anorexia/cachexia syndrome.
- Assessment and treatment of anorexia and cachexia include determining whether exogenous etiologies such as nausea and pain are involved and undertaking vigorous treatment of any such etiologies if present.

Introduction

Management of anorexia/cachexia syndrome (ACS) requires a multimodal, interdisciplinary approach utilizing pharmacological, nonpharmacological, and psychosocial interventions. Anorexia is defined as the reduction or loss of desire to eat[1] and is a symptom that accompanies many common illnesses. In acute events, anorexia usually resolves with resolution of the illness, and any weight lost may be replaced with nutritional supplements or increased intake. Unchecked, anorexia leads to insufficient caloric intake and protein-calorie malnutrition. Weight loss from this starvation phenomenon usually involves loss of fat, rather than muscle tissue.[2] Anorexia is common among patients with advanced cancer and advanced acquired immune deficiency syndrome (AIDS) but also characterizes the clinical course of patients with other chronic progressive diseases, such as chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), and end–stage renal disease.[3–6]

Anorexia and cachexia are two distinct clinical syndromes but are often intertwined in chronic progressive disease. Cachexia is a complex syndrome that usually involves anorexia along with significant weight loss, loss of muscle mass with or without fat wasting, and generalized weakness associated with increased protein catabolism and inflammatory response.[7] The word "cachexia" is derived from the Greek *kakos*, meaning bad, and *hexis*, meaning condition or appearance; throughout medical history, cachexia has been associated with the gravely ill.[7,8] The first clinical definition can be traced to Hippocrates earlier than 400 BC: "The flesh is consumed and becomes water . . . the abdomen fills with water, the feet and legs swell, the shoulders, clavicles, chest and thighs melt away . . . the illness is fatal."[7] It is important to differentiate the cachexia syndrome from simple anorexia or starvation. Anorexia resulting in decreased intake is usually a component of both phenomena, but cachexia can still be found in the absence of decreased appetite.[9] Anorexia alone does not account for the magnitude of weight loss seen in diseases like cancer, and nutritional supplementation does not restore the lean body mass of cancer ACS.[9] Two separate international groups came together in 2008[10] and 2011[11] to develop operational definitions of cachexia, diagnostic criteria, and classification in the hopes of advancing future clinical practice and outcome measures for future clinical trials. In 2011, Fearon and colleagues provided this definition of cachexia:

> Multifactorial syndrome characterized by an ongoing loss of skeletal mass (with or without loss of fat mass) that cannot be fully reversed by conventional nutritional support and leads to progressive functional impairment. The pathophysiology is characterized by a negative protein and energy balance driven by a variable combination of reduced food intake and abnormal metabolism.[11]

Cachexia is a devastating multifactorial syndrome that occurs in more than 80% of patients with cancer before death and is the main cause of death in more than 20% of such patients.[7,8,12] In contrast to the starvation seen in anorexia, in cachexia there is approximately equal loss of fat and muscle, significant loss of bone mineral content, and no response to nutritional supplements or increased intake.[8]

Weight loss, regardless of etiology, has a decidedly negative effect on survival, and loss of lean body mass has an especially deleterious effect.[10,13] Evidence-based reviews about prognosis reveal a significant correlation between anorexia/cachexia and survival in newly diagnosed cancer patients and in patients with advanced disease.[6,13] Weight loss is also linked to decreased survival in CHF, COPD, end-stage renal disease, and AIDS.[4,12,14–17] The term "anorexia/cachexia syndrome" has been used mostly in reference to patients with cancer, and thus the condition is sometimes termed "cancer-related anorexia/cachexia" (C-ACS).[9,12] A classification system for cancer cachexia has been developed with three stages of clinical relevance: pre-cachexia, cachexia, and refractory cachexia[11,18,19] with the hope that it will improve ease of cachexia recognition by clinicians through objective and standardized criteria. Varied terminology has been used to describe the syndrome in other disease states: for instance, HIV wasting syndrome, cardiac cachexia, pulmonary cachexia syndrome, and, in patients with advanced renal disease, malnutrition-inflammation-cachexia syndrome (MICS).[20] Table 11.1 lists the various terms used to describe anorexia-cachexia and estimated prevalence in different disease states. The pathophysiology and clinical presentation of ACS overlap in these various diseases even though the underlying metabolic and neurohormonal imbalances may differ.

Table 11.1 Anorexia/cachexia syndrome in various disease states

Disease	Terminology	Estimated prevalence: highest in advanced disease
Cancer	Cancer-related ACS	Up to 86%
CHF	Cardiac cachexia	16–36%
COPD	Pulmonary cachexia syndrome	30–70%
HIV disease	HIV wasting syndrome	10–35%
Renal disease	MIC: malnutrition-inflammation cachexia syndrome	30–60%

Source: References 6, 7, 12, 15, 16, 17, 30.

The basic issue of underlying chronic inflammation can be seen in them all.[7,10,21] For the purposes of this chapter, the term ACS refers to all chronic, advanced disease–related anorexia/cachexia syndromes.

The ACS of all diseases is characterized by a variety of signs and symptoms that represent interference with energy intake (decreased appetite, early satiety, taste changes, etc.) and nutritional status that include increased metabolic rate, weight loss, hormonal alterations, muscle and adipose tissue wasting, fatigue, and decreased performance status.[9,22] Whatever the specific disease, the development of ACS poses a significant clinical problem. It is a grave prognostic sign but also has a detrimental effect on quality of life (QOL), as documented by studies of all the preceding major diagnoses. This syndrome leads to serious physical and functional deficits and can be devastating to self-image, social and family relationships, and spiritual well-being.

Pathophysiology of Anorexia/Cachexia Syndrome

The basic etiologies of ACS are (1) decreased food intake, (2) metabolic abnormalities, (3) the actions of pro-inflammatory cytokines, (4) systemic inflammation, (5) neurohormonal dysregulation, (6) tumor by-products, and (7) the catabolic state.[23,24] These result in derangement of function with negative effects on survival and QOL. There is within some of these mechanisms a mutually reinforcing aspect; for example, anorexia leads to fatigue, fatigue increases anorexia, anorexia increases fatigue, and so on.[24] Table 11.2 summarizes the mechanisms and effects of ACS.

Table 11.2 Mechanisms and effects of anorexia/cachexia syndrome

Mechanisms	Effect
Loss of appetite	Generalized host tissue wasting, nausea or "sick feeling," loss of socialization and pleasure at meals
Reduced voluntary motor activity (fatigue)	Skeletal muscle wasting and inanition (fatigue)
Reduced rate of muscle protein synthesis	Skeletal muscle wasting and asthenia (weakness)
Decreased immune response	Increased susceptibility to infections
Decreased response to therapy or treatment intolerability	Earlier demise and increased complications of illness

Source: References 2, 22, 24, 46.

The ACS is categorized as primary or secondary, depending on its etiology. *Primary* ACS results from endogenous metabolic abnormalities such as cytokine production, which stimulates chronic inflammation and resulting catabolism. The syndrome is called *secondary* if it results from exogenous etiologies caused by symptoms that interfere with the intake or absorption of nutrients. Examples of such interfering symptoms are pain, nausea, intestinal obstruction, or psychosocial distress.[21]

Primary Anorexia/Cachexia Syndrome

The pathogenesis of primary ACS is multifactorial, complex, and incompletely understood. Accumulating evidence suggests that chronic illness disrupts the homeostatic function of the central nervous system, leading to profound metabolic changes. Peripheral input causes the awareness of threats such as a growing tumor or cardiac or renal failure, and this promotes a catabolic effect which results in increased energy expenditure, reduced intake, increased muscle breakdown, and loss of adipose tissue.[1,21,25,26]

Metabolic Alterations

Metabolic alterations are common in cancer and other diseases and are thought to be due in large part to the systemic inflammatory response and stimulation of cytokine production (principally tumor necrosis factor alpha [TNF-α], prostaglandins [PG], interleukin-1 [IL-1], interleukin-2 [IL-2], interleukin-6 [IL-6], interferon α [IFN-α], and interferon β [IFN-β]). Other catabolic tumor-derived factors thought to play a role in cachexia include proteolysis-inducing factor (PIF) and lipid-mobilizing factor (LMF).[1,8,27] Major metabolic alterations include glucose intolerance, insulin resistance, increased lipolysis, increased skeletal muscle catabolism, negative nitrogen balance, and, in some patients, increased basal energy expenditure.[28]

A number of different theories regarding the pathophysiology of ACS continue to be studied. The maladaptive activation of oxidative processes that may be seen in chronic illness are also thought to be partially responsible for the cachexia syndrome.[27,29] Recent advances in genomics suggest that specific genetic polymorphisms contribute to the prominent inflammatory component of this problem.[29] The melanocortin system of the hypothalamus, which coordinates appetite and feeding, is influenced by peptide hormones such as leptin and ghrelin.[8,27] Disturbances in these hormonally regulated feedback loops appear to play a role in ACS. Other potential mediators of ACS include testosterone, insulin-like growth factor-1, myostatin, and adrenal hormones.[27] In sum, the underlying pathophysiological processes of ACS are complex and not yet fully understood. Researchers postulate that the preceding mechanisms play different roles of varying importance in different diseases.[1,8,28] The relative importance of these factors and the interplay among them remains unclear. However, irrespective of the underlying mechanism or specific medical illness, patients experience progressive worsening of their clinical condition and, ultimately, shorter survival soon after the development of cachexia.[19]

Secondary Anorexia/Cachexia Syndrome

Secondary causes of ACS include exogenous factors that can frequently lead to weight loss, anorexia, fatigue, or other symptoms associated with this wasting syndrome.

Physical Symptoms

A number of physical symptoms of advanced disease may contribute to or cause anorexia, including pain, dysgeusia (abnormalities in taste, especially aversion to meat), ageusia (loss of taste), hyperosmia (increased sensitivity to odor), hyposmia (decreased sensitivity to odor), anosmia (absence of sense of smell), stomatitis, dysphagia, odynophagia, dyspnea, hepatomegaly, splenomegaly, gastric compression, delayed emptying, malabsorption, intestinal obstruction, nausea, vomiting, diarrhea, constipation, inanition, asthenia, various infections (see later discussion), and early satiety.[8,9] Alcoholism or other substance dependence may also contribute to or cause anorexia. Primary or metastatic disease sites have an effect on appetite, with cancers such as gastric and pancreatic having direct effects on organs of alimentation.[2,12,28]

In general, people who are seriously ill and/or suffering distressing symptoms have poor appetites. In addition, in cancer, metabolic paraneoplastic syndromes such as hypercalcemia or hyponatremia (syndrome of inappropriate antidiuretic hormone secretion) may also cause anorexia or symptoms such as fatigue that contribute to anorexia. Patients with HIV disease may also develop primary muscle disease, leading to weight loss.[30] Many treatments for chronic diseases have deleterious effects on appetite or result in side effects leading to anorexia and/or weight loss.[31] Each of these should be ruled out as a contributing cause of anorexia and, if present, treated as discussed elsewhere in this textbook.

Treatment Side Effects

Many interventions used to treat advanced chronic disease have adverse effects on nutritional status. The many medications used to treat HIV/AIDS and its sequela are an excellent example. Despite the success of highly active antiretroviral therapy (or HAART) in curbing ACS in many patients, the myriad medications involved in the prevention and treatment of AIDS complications often lead to anorexia and malabsorption themselves, and HIV wasting remains a problem for many.[30] Cytotoxic drugs can be emetogenic, cause taste changes, or precipitate other gastrointestinal (GI) side effects such as oral stomatitis and diarrhea.[23] Radiotherapy can also lead to significant side effects, including nausea, vomiting, diarrhea, xerostomia, and severe fatigue.[9] Among patients with advanced renal disease on dialysis, there is a high prevalence of protein-energy malnutrition.[4,20]

Psychological and/or Spiritual Distress

Psychological and spiritual distresses are often overlooked causes of anorexia. The physical effects of the illness and/or treatment coupled with psychological responses (especially anxiety and depression) and spiritual distress may result in little enthusiasm or energy for preparing or eating food. As weight is lost and energy decreases, changes in self-image occur. Appetite and the ability to eat are key determinants of physical and psychological QOL.[32,33] Cultural influences must always be considered. For many patients, the net result of ACS and weight loss constitute a negative-feedback loop of ever-increasing magnitude and suffering in multiple dimensions.[34] Clinicians evaluating patients with anorexia are encouraged to review basic principles for the assessment and management of depression, as covered in detail in Chapter 22. Treatment of underlying depression can improve appetite considerably.

Oral Issues

Special attention should be directed toward the oral cavity of patients with advanced disease. The fit of dentures may change with weight loss, or already poorly fitting dentures may not be as well tolerated in advanced disease. Dental pain may be overlooked in the context of terminal illness. Oral and esophageal infections and complications increase with disease progression and immunocompromise. Xerostomia and worsening of tooth decay can occur with radiation therapy to the head and neck region. Basic oral hygiene can often be neglected in the setting of advanced illness. Aphthous ulcers, mucositis, candidiasis, aspergillosis, herpes simplex, and bacterial infections cause oral or esophageal pain and, thus, anorexia.[22]

Assessment

Anorexia and weight loss may begin insidiously with only decreased appetite and slight weight loss, which can accompany virtually any illness. As the disease progresses and comorbid conditions increase in number and severity, anorexia and malnutrition increase, and a mutually reinforcing process may emerge. Cachexia has long been considered a part of advanced disease and end of life. However, skeletal muscle loss may be present earlier in the disease trajectory, and the early stages may be missed in patients with underlying obesity.[12,21] Early identification is optimal, but further research is needed to more clearly define the benefits of early assessment and intervention on patient outcomes.[21,35]

With ACS common and in many cases inevitable among patients with advanced or terminal illness, identifying specific causes is an extremely challenging task. Several international workgroups have proposed guidelines for the definition and classification of anorexia and cachexia.[10,11] More specifically, an international consensus exists on the framework for the definition of cachexia, diagnostic criteria, and classification of cancer cachexia. Future validation of these frameworks should ultimately aid in future study trials, leading to universally accepted guidelines and routine clinical management.[11,21] There have been standardized tools for the general assessment of nutrition status, but none specific to ACS for palliative care.[36] Nevertheless, anorexia from some etiologies is treatable; hence, assessment of the possible presence of etiologies noted previously is integral to quality palliative care. Assessment parameters are used according to the patient's ability to tolerate and benefit from the assessment.

Assessment parameters should include appetite, nutritional intake, and basic nutritional status.[21] Appetite is a component of several well-validated tools of global symptom assessment, such as the Edmonton Symptom Assessment Scale,[37] the Memorial Symptom Assessment Scale,[38] or the visual analog scale (VAS).[39] In addition, simple assessment questions about change in appetite can be transformed into a numerical assessment scale. Intake can be measured retrospectively by recall or prospectively by calorie count. Detailed exploration with appropriate physical examination can identify associated factors (i.e., dysphagia, nausea, oral issues, or pain). Open-ended questions can be helpful in eliciting specific characteristics of the eating problem.

A variety of methods can be used to assess nutritional status, from basic tools such as the Subjective Global Assessment for Nutrition (SGA)[36,40] and its modified patient-generated subjective global assessment (PG-SGA)[41,42] to sophisticated anthropometric and laboratory testing.[6] Common lab values may reveal decreased serum albumin, a prognostic indicator of increased morbidity and mortality, as well as changes in several electrolyte and mineral levels.[6] Other patient-rated tools like Functional Assessment of Anorexia/Cachexia Therapy (FAACT) or its Anorexia/Cachexia Subscale (A/CS) have been developed for clinical trials for orexigenic (appetite-stimulating) agents for cancer- or HIV-related anorexia and are too cumbersome for routine patient evaluation.[6]

Perhaps the most important component of assessment in ACS involves the patient's goals of care. Since palliative care encompasses the entire disease continuum, stage of illness and goals of care should be clearly determined before detailed assessment and intervention are planned or initiated. It is imperative to evaluate the degree of suffering or distress experienced as a result of the ACS. A cost–benefit analysis should be undertaken to determine whether a diagnostic workup is valuable in light of the effort, cost, or discomfort it may incur. At some point in the illness, even basic assessments, such as weight, serve only to decrease the patient's QOL. Assessment parameters are summarized in Box 11.1.

Assessment also includes a psychosocial evaluation, particularly concerning food, determining usual intake patterns, food likes and dislikes, and the meaning of food or eating to the patient and family. Too often, a family member attaches huge significance to nutritional intake and exerts pressure on the patient to increase intake: "If he would just get enough to eat." Giving sustenance is a fundamental means of caring and nurturing, and it is no surprise that the presence of devastating illness often evokes an almost primitive urge to give food. Assessment should also include an evaluation of the patient and family health literacy level, as well as their desire and preferred means of receiving health information.[43]

Box 11.1 Assessment Parameters in Anorexia and Cachexia

The patient is likely to report anorexia and/or early satiety.

Weakness (asthenia) and fatigue are present.

Mental status declines, with decreased attention span and ability to concentrate. Depression may increase concurrently.

Inspection/observation may show progressive muscle wasting, loss of strength, and decreased fat. There often is increased total body water, and edema may thus mask some wasting.

Weight may decrease. Weight may reflect nutritional status or fluid accumulation or loss.

Increased weight in the presence of heart disease suggests heart failure.

Triceps skinfold thickness decreases with protein calorie malnutrition (PCM; skinfold thickness and midarm circumference vary with hydration status).

Midarm muscle circumference decreases with PCM.

Serum albumin concentrations decrease as nutritional status declines. Albumin has a half-life of 20 days; hence, it is less affected by current intake than other measures.

Other lab values associated with ACS include anemia, increased triglycerides, decreased nitrogen balance, and glucose intolerance.

Source: References 8, 17, 34, 42.

In some cases the patient is less troubled than the family by poor nutritional intake. Clinicians should explore the meaning of feeding in the context of the family's cultural and religious background and help identify other ways in which the family can participate in caring for the patient.[43]

Interventions

The palliative approach to care of the patient with ACS focuses on improving patient comfort and minimizing distress caused by the anorexia and weight loss. Assisting patients and families to adapt to progressive symptoms and alleviating symptoms that may be exacerbating the problem are two foci of interventions. Interventions may combine a variety of approaches, including treatment of secondary (exogenous) causes of anorexia, nutritional support, enteral and parenteral nutrition, pharmacological management, and psychosocial support.[44]

Exogenous/Secondary Symptom Management

The presence of symptoms that may cause or exacerbate secondary anorexia and weight loss should be evaluated and treated as possible. If anorexia is due to an identifiable problem, such as pain, nausea, fatigue, depression, or taste disorder, appropriate interventions as discussed elsewhere in this book should be instituted. The goal here is to identify and manage potentially correctible problems that contribute to low dietary intake.[8]

Nutritional Support

Oral nutritional support, in an attempt to increase intake or to maximize nutritional content, may be helpful especially early in the disease process or in specific disease states. For example, there is evidence that nutritional supplementation can be effective in patients with COPD.[45] However, C-ACS studies have been disappointing. The current evidence continues to reveal that, despite best efforts of improving the quantity and quality of nutrition through conventional nutritional support, it does not improve lean body mass in patients with cancer.[9,46] Unfortunately, there is no conclusive evidence that dietary counseling or other conventional nutritional support has increased survival, significant weight gain, or improved QOL with cancer patients, but the overall risks are low and patients and families tend to value this support.[26,33]

Helping family members understand nutritional needs and limitations in terminal situations is essential.[47,48] Consultation with a nutritionist is usually warranted for the purpose of education and recommendation of appropriate supplements. General guidelines for nutritional interventions include the following[22,33,34,49]:

- The nutritional quality of intake should be evaluated and appropriately modified to improve the quality. Patients who are not moribund may benefit emotionally from supplementary sources of protein and calories. Clinicians should determine the meaning to the patient and family of giving, taking, and refusing food. Strong and even unconscious beliefs about food are difficult to modify, and many families require education and frequent support in the face of helplessness and frustration related to ever-diminishing intake.

- Culturally appropriate or favored foods should be encouraged. Preserving cultural or social traditions around meals may also be helpful. Families should be encouraged to share mealtime with patients or continue habits such as a glass of wine with meals, if medically appropriate.
- Small meals, on the patient's schedule and according to the taste and whims of the patient, are helpful, at least emotionally, and should be instituted early in the illness so that eating does not become burdensome.
- Foods with different tastes, textures, temperatures, seasonings, degrees of spiciness, degrees of moisture, and colors should be tried, but the family should be cautioned against overwhelming the patient with a constant parade of foods to try. Room temperature and less spicy foods are preferred by many patients.
- Different liquids should also be tried. Cold, clear liquids are usually well tolerated and enjoyed, though cultural constraints may exist. For example, patients with illnesses that are classified as "cold" by some Southeast Asians and Latinos are thought to be harmed by taking drinks or foods that are either cold in temperature or thought to have "cold" properties.
- Measures as basic as timing intake may also be instituted. Patients who experience early satiety, for example, should take the most nutritious part of the meal first. Filling fluids without nutritional value (such as carbonated soda) should be avoided at mealtime. Oral care must be considered an integral part of nutritional support. Hygiene and management of any oral pain are essential in nutritional support. Procedures, treatments, psychological upsets (negative or positive), or other stresses or activities should be limited prior to meals.

Enteral and Parenteral Nutrition

Enteral feeding (via nasoenteric tube, gastrostomy, or jejunostomy) may be indicated in a small subset of terminally ill patients. Many clinicians postulate that there exist certain patients with a good functional status and relevant secondary (exogenous) component to their ACS who may benefit from invasive nutritional interventions. Examples include patients with head and neck cancer with severe dysphagia who are undergoing radiation therapy, patients with slow-growing tumors causing bowel obstruction, patients undergoing certain surgeries for upper gastrointestinal tract (UGI) malignancies, or those undergoing bone marrow transplant.[50,51] However, the evidence remains insufficient to recommend precise guidelines for specific populations.[50] In general, guidelines recommend against enteral feedings for cancer patients undergoing routine radiotherapy, chemotherapy, or bone marrow transplantation.[8] Furthermore, despite the common practice of placing percutaneous endoscopic gastrostomy (PEG) tubes in patients with head and neck cancer, insufficient evidence exists that prophylactic PEG placement improves clinical outcomes.[50]

The clinical indications for enteral nutrition in noncancer diagnoses remain controversial, perhaps no more so than in the case of dementia. Although more than 30% of patients with dementia in nursing homes have PEGs, the best available data suggest that tube feeding does not improve QOL, reduce pressure ulcer formation or healing, limit aspiration risk, enhance functional capacity, or increase survival.[52] In these patients, careful hand feeding has been recommended as an alternative. Two nonmalignant conditions warrant consideration of enteral feeding. These include patients with stroke who otherwise have good QOL and patients with early amyotrophic lateral sclerosis (ALS).[53,54] In general, patients with poor performance status and poor prognosis are at high risk for mortality from gastrostomy.[50,55] In these patients, comfort feeding should be the primary focus in maintaining QOL.

The use of parenteral nutrition in ACS has been controversial within the palliative care field, and, in nearly all cases, if the patient has a functioning gut, enteral nutrition is preferred over parenteral nutrition because of the latter's very limited benefit and because the former is associated with lower cost and fewer complications.[26,56] In palliative care settings, long-term use of parenteral nutrition should be considered only if aligned with goals of care and in those with good underlying functional status, a prognosis of 2–3 months, and in whom enteral feeding is not possible.[56,57]

Pharmacological Interventions

A plethora of pharmacological studies have targeted C-ACS,[12,21] and recent work includes other chronic advanced disease.[2] The most frequently prescribed and most studied drug is megestrol acetate (MA), a synthetic progesterone agent that acts to increase appetite and weight gain.[58] Although the mechanisms by which MA operate are not well understood, most hypotheses suggest that the medication acts on cytokines, inhibiting TNF, and it may also increase release of neuropeptide Y (NYP) in the hypothalamus, resulting in stimulation of the neurons involved in the satiety mechanism.[8,58] The most recent Cochrane review discussed trials that evaluated the efficacy, effectiveness, and safety of MA in palliating ACS in patients with cancer, AIDS, and other underlying pathologies.[59] The review found that MA improves appetite but has a small effect on weight gain. The review shows that it does not improve QOL and suggests that side effects are more frequent in patients treated with MA.[59] Side effects of MA include hypoadrenalism, hypogonadism, and, most concerning, thrombosis and deep vein thrombosis (DVT).[9,58] Limited data are available regarding the safety of using MA, especially in the long term.[59]

Glucocorticoids are widely used in the palliative care setting to address a number of symptoms, including pain, dyspnea, and nausea.[3] In cancer patients, steroids have been shown to have a limited positive effect on appetite, nutritional intake, and sense of well-being, but no demonstrable effect on weight.[21] The varying use of corticosteroids (dexamethasone, methylprednisolone, or betamethasone), dose quantity, treatment duration, and attrition rates in studies make it difficult to draw firm conclusions on which corticosteroid and dosing is safest to use.[3] The wide range of side effects, especially with longer duration of use, including adrenal suppression, hyperglycemia, and peptic ulceration, may preclude their use in some patients. However, some suggest that corticosteroids may be more suitable for patients with shorter life expectancy, especially if they have other symptoms that may be alleviated by this drug, as just suggested.[21]

Cannabinoids have shown similar positive effects: improved appetite and mood but without weight gain.[1,8] At least two of the US Food and Drug Administration (FDA)-approved cannabinoids are available in the United States: dronabinol (approved for treatment of anorexia associated with weight loss in patients with HIV/AIDS and for treatment of refractory chemotherapy-induced nausea and vomiting) and nabilone (approved only for treatment of refractory

Table 11.3 Medications commonly used in anorexia/cachexia syndrome

Medication effects and common dosing	Indications	Side effects and considerations
Progestational agents esp: Megestrol acetate 160–800 mg/day	Improves appetite, weight gain, and sense of well-being	Thromboembolic events, glucocorticoid effects, GI upset/problems, heart failure, menstrual abnormalities, tumor flare
Corticosteroids e.g.: Dexamethasone 3–6 mg/day (considered preferable due to its lower mineralocorticoid effect) Prednisone 20–30 mg/day	Improves appetite and sense of well-being	Immunosuppression, masks infection, HTN, myopathy, GI disturbances, dermal atrophy, increased ICP, electrolyte imbalances, anxiety, avoid abrupt cessation
Cannabinoids: Dronabinol 5–20 mg/day	Increases appetite and decreases anxiety	Somnolence, confusion, dysphoria, especially in elderly
Metoclopramide 10 mg before meals	Improves gastric emptying, decreases early satiety, improves appetite	Diarrhea, restlessness, fatigue, drowsiness, extrapyramidal side effects

HTN, hypertension; ICP, intracranial pressure.

Source: Reference 6, 8, 58, 60, 63.

nausea and vomiting associated with chemotherapy).[6] However, the central nervous system side effects and difficulty in dosing limits the use of this medication.[26] Commonly used pharmacological options with indications and notable side effects are presented in Table 11.3.[60]

Since June 2017, 29 US states and the District of Columbia have medical marijuana programs, although marijuana remains illegal under federal law.[61] As of yet, there are no controlled clinical studies to support marijuana's efficacy for symptom management in conditions such as ACS.[6] Additionally, there can be distressing central nervous system side effects, particularly for older populations.[9,61] Based on the medical and legal concerns, the use of medical marijuana is not included in any domestic treatment guidelines.

Future directions in pharmacological management target various pathways implicated in ACS. Neurohormonal manipulation, cytokine inhibition, and anti-inflammatory interventions all show some promise in clinical trials.[9,31,46]

The peptide hormone ghrelin is a circulating mediator of appetite and has been implicated in ACS. Early trials that supplement ghrelin in various illnesses have shown short-term increases in caloric intake in patients with cancer and renal failure[9] and improved lean body mass and exercise capacity in those with COPD and CHF.[62] An oral ghrelin mimic, anamorelin, seems to have shown the best progress toward approval after early-phase trials showed increased food intake, appetite, and lean body mass in patients with cancer.[21,63] In preliminary studies, selective androgen receptor modulators and ghrelin mimetics have an overall positive effect on lean body mass but not on function. As a result, they have not been approved for clinical use.[64]

Thalidomide is a controversial medication of interest to ACS researchers. Previously withdrawn from the market due to its teratogenic side effects, thalidomide is now under study in advanced disease due to its potent antiemetic and TNF and IL-6 inhibitor activity.[8] Although its safety profile remains a concern, this medication may be a useful option and is under study.[9] Other medications under study include melanocortin (thought to decrease circulating TNF); various anabolic steroids, such as growth factor, insulin like growth factor, and testosterone derivatives; omega-3 polyunsaturated fatty acids (as found in fish oils); the antidepressant mirtazapine; the atypical antipsychotic olanzapine; beta-adrenergic agonists; and anti-inflammatory medications (i.e., COX-2 inhibitors).[1,6,8,9,24,56] While further research continues, these agents have shown some benefit in lab and in limited clinical studies. There is also increasing evidence that, given the multifactorial process involved in ACS, treatments involving combinations of agents may show promise.[21,31]

Psychosocial Support

Anorexia and cachexia can have a profound impact on the QOL of patients, not only heralding physical decline but also leading to significant emotional and social distress.[8,49,65] Weight loss negatively affects patient self-esteem but can cause even more distress and anxiety among family and partners. In a descriptive study by Reid and colleagues,[65] patients viewed wasting as a social stigma and an ominous prognostic sign. However, family held on to beliefs that weight loss was a result of decreased appetite alone. Conflict over food was a common consequence of such dissenting views. Lack of education and a strong symbolic attachment to food increased distress.[26,65] Nurses can play a critical role in assessing patients and family and providing sensitive and culturally appropriate education and support.[66]

Multimodal Approach

The devastating psychosocial consequences, pathophysiological complexities, and treatment resistance of ACS lead inevitably to consideration of a multimodal approach.[2,34,43,45] A summary of what should be included in this approach is summarized in Box 11.2.

Case Study: Some Issues Commonly Associated with Anorexia/Cachexia Syndrome

Mr. G is a 58-year-old man with stage 4 bladder cancer (metastatic to peritoneum and liver) who was recently admitted to the

Box 11.2 Components of a Multimodal Approach to Anorexia/Cachexia Syndrome

1. Early and ongoing determination of goals of care
2. Optimal treatment of underlying disease according to goals of care
3. Prevention, recognition, and prompt treatment of exogenous causes
4. Guidance from nutrition specialists
5. Appropriate pharmacological interventions
6. Resistance exercise as appropriate
7. Compassionate counseling to patient, family, and significant caregivers with clear, consistent, and empathetic dialogue

Source: References 12, 43, 48, 62, 66.

hospital from home with decreased oral intake, vomiting, nausea, and new onset abdominal pain. He received his most recent palliative chemotherapy 1 month ago and was tolerating the treatment well. Over the past several weeks, he was spending most of his day in bed since the onset of his symptoms and reported that his husband was struggling to care for him at home. Mr. G reports that he has not had stool output from his colostomy in more than 1 week, and he has not been able to tolerate food or liquids without vomiting over the past 2 days. He reports that he has had a poor appetite for many months, and he has lost 10 pounds since his last chemotherapy. Low-dose intravenous morphine was initiated to treat his abdominal pain, as was conservative medical management of his partial small bowel obstruction (SBO) related to tumor burden diagnosed on admission. His partial SBO resolved, and he was able to tolerate small, more frequent liquid nutritional supplements, but reports that he is “forcing myself to eat.” He also reported that he continues to have some underlying nausea that interferes with his eating. After a nutrition evaluation, Mr. G was determined to have severe malnutrition, and he had a workup for a potential enteral feeding tube placement to assist with nutritional support. After many past debulking and other abdominal surgeries, his anatomy would not permit an enteral feeding tube, and it was determined he was not a candidate for parenteral feeding. The primary, oncology, and palliative care teams worked closely with Mr. G and his husband to determine his goals and assess his needs moving forward, uncovering educational gaps and promoting management options and support. Mr. G decided that he wanted to trial a short stay at a skilled nursing facility (SNF) to allow a chance to “regain some of my strength with the goal of going home.” He reports that home hospice is something he has thought about and will continue to consider moving forward. The palliative care team initiated low-dose dexamethasone 4 mg/day orally with some slight improvement of patient’s appetite but significant relief of his underlying nausea. Mr. G also reported some improvement of his appetite with dronabinol in the past, so twice-daily dosing of dronabinol 2.5 mg/day orally was also initiated with significant improvement in his appetite. Prior to Mr. G’s discharge to an SNF, he was stabilized and his symptoms were controlled with a clear plan in place.

Conclusion

Increasingly, ACS is recognized as a serious aspect of advanced or terminal illness and as an area requiring further research, especially with respect to (1) the pathophysiology of cachexia and (2) increasing treatment options.

The management of ACS is complicated by numerous obstacles, including lack of clear definitions and guidelines, inconsistency in assessment and management strategies, and knowledge deficits about this complex clinical syndrome in health professionals and caregiving families. The challenge is compounded by the interwoven emotional symbolism of food and nurturance. As palliative care providers, we should strive to support, understand, and translate the developing evidence that guides our care. The complex and potentially devastating impact of this problem demands a holistic response. Palliative care nurses are optimally situated to coordinate and drive the necessary multidisciplinary approach to address anorexia and cachexia in advanced, progressive disease.

Current understanding of ACS includes the following:

- Anorexia and cachexia are distinct syndromes but clinically difficult to differentiate.
- Anorexia is characterized by decreased appetite that may result from a variety of causes (including unmanaged symptoms such as nausea and pain). It results primarily in loss of fat tissue, and resultant weight loss is reversible.
- Cachexia is a complex metabolic syndrome thought to result from the production of pro-inflammatory cytokines such as TNF and IL-1. In cachexia, there is approximately equal loss of fat and muscle and significant loss of bone mineral content. Weight loss from cachexia does not respond to nutritional interventions.
- In 2011, an international consensus defined cachexia as a multifactorial syndrome characterized by an ongoing loss of skeletal mass (with or without loss of fat mass) that cannot be fully reversed by conventional nutritional support and leads to progressive functional impairment. The pathophysiology is characterized by a negative protein and energy balance driven by a variable combination of reduced food intake and abnormal metabolism.[11]
- Assessment and treatment of ACS include determination of whether exogenous etiologies such as nausea or pain are involved, the vigorous treatment of any such etiologies, and nutritional and psychosocial support if indicated.
- Treatment of cachexia is unsatisfactory, and no single pharmacologic agent successfully treats it, so a multimodal approach as discussed earlier is recommended.

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CHAPTER 12

Nausea and Vomiting

David Collett and Kimberly Chow

Key Points

- Nausea and vomiting are symptoms commonly experienced in advanced disease although the majority of available research continues to focus on the cancer population.
- The cause of nausea and vomiting is often multifactorial and requires a thorough assessment and understanding of the emetic pathway and neurotransmitters involved in order to aid treatment decisions.
- Pharmacological and nonpharmacological interventions should be considered when managing the distressful symptoms of nausea and vomiting, with treatment tailored to the individual needs and goals of each patient.
- Nurses play a vital role in helping patients and family members manage and cope with nausea and vomiting.

Introduction

Nausea and vomiting are symptoms commonly experienced by patients with chronic and advanced illness. These highly distressing symptoms may be directly or indirectly related to disease and can have a significant impact on both the physiological and psychological well-being of patients.[1] Physiological repercussions of poorly controlled nausea and vomiting include metabolic disturbances, malnutrition, electrolyte imbalances, and impairment of functional ability as well as unnecessary hospitalizations, emergency room visits, and interruptions in disease-related treatments.[2–4] Psychologically, nausea and vomiting, whether experienced together or separately, can cause distress, anxiety, and fear, leading to the erosion of one's quality of life (QOL) in multiple domains, and they may also cause strain on caregivers.[1]

To date, the majority of research on nausea and vomiting focuses on the oncology population, with an emphasis on treatment-induced symptoms in patients receiving disease-directed therapy for either curative or palliative purposes. Despite advances in antiemetic therapies over the past three decades, nausea and vomiting continue to be some of the most feared and distressing symptoms reported by patients.[1,5] Larger organizations including the National Comprehensive Cancer Network (NCCN), American Society of Clinical Oncology (ASCO), and the American Nurses Association (ANA) have embraced palliative care as part of comprehensive cancer care starting at diagnosis to improve patient outcomes and QOL throughout treatment.[2,6,7] As such, palliative care clinicians must work alongside primary disease management teams to ensure the proper palliation of these bothersome symptoms. Doing so can improve QOL and allow patients to more comfortably continue on with appropriate life-saving or life-prolonging therapies if this is in line with their goals of care.

Unfortunately, the literature on the prevalence, assessment, and management of nausea and vomiting in the noncancer population is lacking. Advances in healthcare and technology have led to increased survival across various disease populations, with patients now living longer with chronic illness and the potential for high symptom burden. More research is needed to better understand the prevalence and etiology of noncancer nausea and vomiting to develop treatment regimens that are disease- and patient-specific.

Given the available evidence, this chapter will use advanced cancer patients as a model for assessment and treatment of nausea and vomiting, which can then be extrapolated for use in other patients with noncancer diseases. Understanding the emetic pathway and main neurotransmitters involved in this process may be one place to start.[8] Methods for proper symptom management, including screening, preventing, assessing, treating, and follow-up, will be explored, and nursing interventions and patient and family education will be highlighted.

Epidemiology of Nausea and Vomiting in Palliative Care

The extent of patient suffering with any serious illness is largely determined by the presence and intensity of disease-related symptoms. An understanding of symptom prevalence in different diseases will allow clinicians to anticipate problems for the patient, develop plans of care, and educate clinical staff.

The prevalence and severity of nausea and vomiting specifically in the palliative care population have been difficult to capture for various reasons including lack of standardized tools to measure symptoms and the common misconception that nausea and vomiting occur as a single entity when they are, in fact, two individual symptoms.[8] While they should be viewed as symptoms independent of each other, it is common for nausea and vomiting to form a highly distressful symptom cluster. Symptom clusters have been described as a stable group of two or more interrelated symptoms that often occur together, and studies have looked at their effects on QOL and treatment approaches.[9–11] Gastrointestinal (GI)-specific clusters may include nausea, vomiting, appetite loss, taste change, and/or constipation. In one study looking at patients with bone metastases receiving radiation therapy, nausea was found to cluster with shortness of breath and poor appetite.[1,12] Understanding the pathophysiology of these clusters may lead to a better and more effective approach to symptom management that targets multiple rather than individual symptoms.[10,13]

Cancer Population

Prevalence of nausea and vomiting in patients with advanced cancer has been reported between 20% and 70% and is described by patients as one of the most dreaded side effects of cancer treatment.[3,14,15] Research on nausea and vomiting over the past three decades has led to steady improvements in the control of chemotherapy-induced nausea and vomiting (CINV), with the development of 5-hydroxytryptamine3 (5HT3) receptor antagonists in the 1990s being one of the most significant advances in symptom management for patients receiving chemotherapy.[14,16]

Despite these advances, approximately 30–50% of patients' post-chemotherapy administration will experience nausea, vomiting, or both.[1,2,17] Oncology patients may experience these symptoms because of disease and/or treatment. The incidence, prevalence, and severity is related to the emetic potential of the chosen treatment regimen and specific patient variables, with some studies suggesting that female gender and younger age are predisposing factors for CINV.[2,3,8,18]

The data on the prevalence of nausea and vomiting at end of life in cancer patients are mixed and have been reported as high as 70% in the last weeks of life.[8,16,18,19] The severity of symptoms is related to cancer type, whether the patient is still receiving disease-targeted therapies, and acute issues that may occur as the disease progresses. One acute complication of some cancers is malignant bowel obstruction (MBO), which is a common cause of morbidity and death in patients with advanced GI and gynecological malignancies. Prevalence of MBO ranges from 25% to 50% in colon cancer, 16% to 29% in ovarian cancer, and 6% to 19% in the gastric cancer population.[20] Common clinical signs and symptoms of MBO include nausea, vomiting, lack of stool or flatus, and abdominal pain. Severity of symptoms is usually associated with the degree of obstruction.[21]

Noncancer Population

Nausea and vomiting for patients with noncancer serious illness has received less attention, and available research provides conflicting information. Similar to the cancer population, drawing firm conclusions regarding the epidemiology of nausea and vomiting in the noncancer population is complicated by methodological difficulties and the lack of standardized symptom definition and reporting.[8,22,23]

One large retrospective cohort analysis of patients receiving community-based palliative care, 90% with noncancer diagnoses, found that lower palliative performance status (PPS) was associated with higher scores of pain, depression, nausea, and constipation.[24] Other studies suggest that nausea and/or vomiting are experienced by people with advanced illness, such as AIDS, congestive heart failure, chronic liver disease, and chronic kidney failure, but not as commonly as pain, breathlessness, or fatigue.[8,23]

In the heart failure population, particularly at end of life, the prevalence of nausea ranges from 11.2% to 48%, with more than half reporting only partial or no relief of this distressing symptom.[25,26] For patients with chronic renal failure, prevalence of nausea ranges from 30% to 44% during the various stages of illness and shifts toward 13% to 34% at the end of life after discontinuation of dialysis. During the end stages of renal disease, nausea has been known to cluster with other symptoms related to uremia such as lack of appetite, dizziness, shortness of breath, and chest pain.[25,27,28] Patients with cirrhosis who are not candidates for liver transplantation have high symptom burden and palliative care needs, with the presence of nausea documented as high as 58%.[29]

An important population of patients with both cancer and noncancer diagnoses to consider are those residing in long-term care facilities. Nearly one of every four deaths in the United States occurs in these settings, with numbers expected to increase to as high as 40% in 2040 as the population ages.[30] Some of the challenges to appropriate symptom management in long-term care facilities are the lack of palliative care–trained staff, high staff turnover rates, and the lack of physician or advanced practice provider presence. The residents at these facilities often have high rates of serious comorbid conditions including cancer, progressive neurodegenerative conditions, and other diseases that impair functional status and the ability to communicate.

In this setting, nausea seemed to occur less frequently than pain, dyspnea, or constipation. Symptoms may also be underreported and undertreated especially for these patients who often have multiple comorbidities.[22,30] In one study looking at the palliative care needs of 49,172 deceased nursing home residents during the final week of life, 11.1% reported nausea compared to 58.7% reporting pain, the most prevalent symptom.[22] Although research has been conducted on assessing and managing pain in these settings, further studies on nonpain symptoms are necessary.

Conceptual Concerns Related to Nausea and Vomiting

The terms "nausea" and "vomiting," often clinically associated, are in fact distinct concepts that are many times mistakenly used interchangeably or imprecisely, impacting the ability to assess and measure prevalence and burden.[8] *Nausea* is an unpleasant feeling of the need to vomit experienced in the back of the throat and epigastrium. The patient often describes the sensation as feeling "queasy" or "sick to my stomach" or may have a difficult time describing the unpleasant sensations experienced.[3,8,31,32] *Vomiting* is a physical event that results in the forceful expulsion of gastric contents from the stomach through a complex reflex involving the GI tract, diaphragm, and abdominal muscles. This may be described as "barfing," "upchucking," or "puking."[3,32] The two should always be assessed separately. *Retching* is similar to vomiting without the actual expulsion of material.[3] Patients often describe this as "gagging" or "dry heaves."

While there are multiple etiologies for nausea and vomiting in advanced cancer, CINV is one of the most common and can continue even near death as many patients remain on systemic therapy in the late stages of their disease. Three distinct types of CINV have been described. The acute phase can occur within minutes of administration and commonly resolves within 24 hours, with the greatest symptom intensity after 5–6 hours. The delayed phase usually occurs 24 hours following treatment, with peak intensity between 48 and 72 hours. Anticipatory nausea and vomiting differs from the other two; it is a response to conditioned stimuli developed from significant nausea and vomiting during previous chemotherapy treatments and occurs even before treatment is administered.[2,5]

Physiological Mechanisms of Nausea and Vomiting

Understanding the pathophysiology of nausea and vomiting is important for optimal management of a patient with these symptoms. Having knowledge of the mechanisms allows for a rational selection of pharmacological and nonpharmacological therapies or interventions to address the cause.

Vomiting occurs when the vomiting center, located in the medulla oblongata, is activated by peripheral and central afferent pathways. Peripherally, afferent nerves from the GI tract activate the vomiting center when there is pathology such as mucosal irritation, bowel wall invasion by neoplasm, or activation of stretch receptors. Stretching of the bowel lumen, as well as stretching of the capsule on visceral organs, can activate the afferent neural circuit. The gag reflex occurs when the glossopharyngeal nerve (cranial nerve IX) is stimulated in the pharynx by coughing or other mechanical irritation.[33] Central neural circuits that induce vomiting include the chemoreceptor zone and the cortex. The chemoreceptor trigger zone (CTZ) is a vascular region in the area postrema of the fourth ventricle and is outside of the blood–brain barrier.[34]

Chemical irritants (e.g., medications), electrolyte disturbances (e.g., hypercalcemia), and infections stimulate the CTZ. Vomiting that occurs when our senses of smell, taste, sight, or hearing are stimulated or vomiting associated with fear or anxiety, is cortical. The nausea and vomiting that occurs with motion sickness or vertigo is mediated by the vestibulocochlear nerve. Vomiting that is prominent in the morning can be associated with increased intracranial pressure (ICP).[35] The neural pathway for nausea and vomiting associated with increased ICP is less understood than other neural pathways to the vomiting center. Figure 12.1 is a conceptual illustration of the described pathways that lead to nausea and vomiting.

The afferent pathways and the vomiting center rely on specific neurotransmitters that result in nausea and emesis when there is an appropriate stimulus. For example, enterochromaffin cells in the gut release serotonin when there is mucosal irritation from chemotherapeutic agents. The released serotonin binds to its receptor and this afferent signal is transmitted to the vomiting center. Previously, it was believed that chemotherapy caused nausea and vomiting primarily by triggering the CTZ. Now it is understood that irritation of the gut and resultant serotonin activation of the peripheral afferent pathway from the gut are important causes, along with central afferent CTZ activation. The neurotransmitters involved in activation of the CTZ are dopamine and serotonin. The vestibular system depends on activation of histamine and acetylcholine to transmit afferent signals to the vomiting center. The vomiting center is rich in serotonin, histamine, and acetylcholine receptors.[8,34,36]

Pharmacological therapies often target these ligand–receptor actions to prevent nausea and vomiting. Serotonin receptor antagonists, such as ondansetron, are particularly helpful for CINV because they block the activation of the GI afferent loop to the vomiting center, as well as inhibit serotonin action in the CTZ and the vomiting center. Neurokinin-1 (NK1) receptor antagonists, like aprepitant, target the neurokinin receptor NK1 that was more recently discovered to be involved in vomiting. The vomiting center is rich in NK1 receptors, and when the usual ligand, substance P, is attached to the receptor, vomiting is induced. [37]

Causes of Nausea and Vomiting

There are numerous potential causes of nausea and vomiting in cancer patients, especially in those with advanced disease. It is helpful to have a thorough understanding of the common causes, which can be subdivided into six clinical

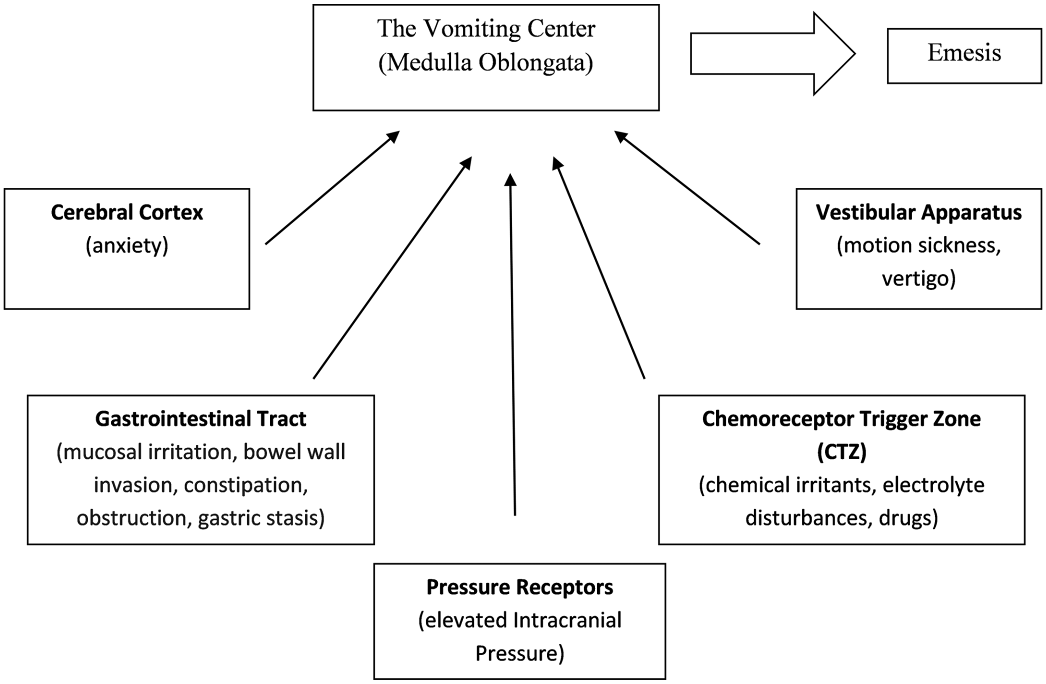
The Vomiting Center
(Medulla Oblongata)
Emesis
Cerebral Cortex
(anxiety)
Vestibular Apparatus
(motion sickness, vertigo)
Gastrointestinal Tract
(mucosal irritation, bowel wall invasion, constipation, obstruction, gastric stasis)
Chemoreceptor Trigger Zone (CTZ)
(chemical irritants, electrolyte disturbances, drugs)
Pressure Receptors
(elevated Intracranial Pressure)

Figure 12.1 Emetic pathways.

syndromes: biochemically/drug-induced, gastric stasis, GI obstruction/irritation, increased ICP, vestibular, and psychological. It is important to remember that common causes may overlap (e.g., drug-induced and psychological causes). These clinical syndromes are presented in Box 12.1.[3,8,15,35,38]

Box 12.1 Common Syndromes Involving Nausea and Vomiting in the Palliative Care Population

Biochemically/Drug-Induced

Fluid and electrolyte imbalances (e.g., hypercalcemia, hyponatremia)

Organ failure (e.g., liver, renal)

Chemotherapy

Medications (e.g., opioids, antibiotics, anticonvulsants, antidepressants)

Gastric Stasis

Carcinoma of stomach

Ascites

Opioid-related

Anticholinergic drugs

Peptic ulcers

Gastrointestinal Obstruction/Irritation

Cancer-related

Esophagitis

Peptic ulcers

Gastric distension or compression

Delayed gastric emptying

Bowel obstruction

Constipation

Biliary obstruction

Intraabdominal spread (e.g., peritoneal disease)

Adhesions

Treatment related (e.g., chemotherapy, radiation)

Infection (e.g., cryptosporidiosis)

Medication (e.g., aspirin, NSAIDs)

Increased Intracranial Pressure

Cerebral edema

Intracranial tumor

Intracranial bleeding

Meningeal disease

Vestibular

Opioid-induced

Cerebral metastases

Motion sickness

Psychological

Fear

Anxiety

Anticipatory

NSAIDs, nonsteroidal anti-inflammatory drugs; SSRIs, selective serotonin reuptake inhibitors

Source: References 3, 8, 15, 35, 38.

Although the potential causes of nausea and vomiting are extensive and the frailty of the palliative care patient often precludes invasive diagnostic testing, studies have shown that it is possible to determine the underlying cause or causes for targeted therapy.[3] Approach to treatment relies heavily on identifying the symptoms present and any patterns, grasping the physiological mechanisms involved, and determining the underlying etiology, keeping in mind that causes are often multifactorial.[15,31] The skilled clinician will use her or his assessment to quickly identify any reasonably reversible causes that remain in line with the patient's and family's goals of care.

Assessment of Nausea and Vomiting

Among the principles of emesis control for the cancer patient is, first and foremost, to prevent nausea and vomiting.[2] When this goal is not achieved, recommendations advocate for a structured approach to assessing and treating these symptoms.[15,34] Assessment is an important process and the foundation of all treatment-related decisions. It should be an ongoing process that begins with the initial patient contact.

The palliative care specialists' approach to symptom assessment and treatment requires understanding of symptom pathophysiology and possible etiologies, which can be obtained from the patient's history, physical exam, and diagnostic test results.[32] It is rare that patients present with nausea and vomiting as a first sign of advanced cancer. Generally, patients who complain of this symptom complex have a well-documented history of their disease, including diagnosis, prior treatment, and sites of metastases. Regardless, a focused exam is needed to narrow down the list of differential diagnoses while paying special attention to causes that may be reversible.[15]

The history of present illness and review of systems should include questions regarding the pattern of symptoms (e.g., time of onset, duration, volume of vomitus), whether the symptoms occur in tandem or in proximity with other symptoms (e.g., epigastric pain, dysphagia, hiccups, heartburn, or constipation), possible triggers (e.g., medications, radiation therapy, meals, position, smells), and previous remedies attempted (e.g., over-the-counter or prescription medications). The clinician should also consider the functional status of the patient and his or her overall prognosis as this can help guide treatment decisions.[15]

A physical exam should be comprehensive to assess for possible etiologies. The oral cavity should be assessed for thrush or mucositis. The abdomen should be visually inspected, auscultated, and palpated to assess for physical signs such as abdominal distension or masses, presence or absence of bowel sounds, and organ enlargement or ascites.[38] A rectal examination should be performed if there is suspicion of impaction. A neurological exam is also recommended, assessing for increased ICP or other neurological

Box 12.2 Rhodes and McDaniel Recommended Criteria for Choosing Instruments to Measure Nausea, Vomiting, and Retching

- Use self-report tools rather than observational assessment whenever possible.
- Check reliability and validity.
- Look for clarity, precision, cultural sensitivity, and understandable wording.
- Instrument should be in an easy-to-read format.
- Determine and describe the symptoms and components.
- Determine a time frame for recall of the symptom experienced.
- Consider the purpose of the tool, the target population, and whether it is for acute, delayed, or anticipatory nausea and vomiting or for patients with advanced cancer.
- Consider the ease of scoring and type of score.

Source: Rhodes & McDaniel (2001), reference 34.

etiologies. Laboratory studies may help rule out organ dysfunction, infection, and electrolyte imbalances; imaging diagnostics should be ordered if indicated to guide treatment decisions.[32,38] Ultrasound, computed tomography (CT) scan, and magnetic resonance imaging (MRI) are all imaging modalities that can be useful to further diagnose etiologies (e.g., small bowel obstruction, intracranial causes).[38]

Information obtained by questionnaires or self-report tools such as diaries or logs is crucial for the identification and management of this symptom complex and for improving the patient's QOL. Rhodes and McDaniel provide clear criteria when trying to choose the appropriate assessment tool for individual patients, summarized in Box 12.2.[34]

There are several measurement tools that may be used to assess one or more of the components of nausea and vomiting. Some tools provide a global measure while others measure a single component of the nausea and vomiting. Instruments may involve checklists, visual analog scales, patient interviews, or Likert scales, and almost all involve self-report by the patient.[1,39,40] The most commonly used tools with reliability and validity reproducible in research studies are shown in Table 12.1.[34,39,41,42]

Nurses working in all settings and with all age ranges of patients need to use skillful observation along with effective data collection techniques for a complete and comprehensive assessment. This is especially applicable in populations that may have difficulty communicating symptoms, such as in pediatric populations, long-term care populations, or with patients with limited abilities to communicate (e.g., cognitive impairment, intubated). Research has shown that caregiver symptom reports can be helpful when making these assessments.[43] Keep in mind that patients with different levels of cognitive or communication ability may still be able to make their needs known and communicate pain and other distressful symptoms. For all patients, early recognition and assessment of symptoms must be tailored to individuals.

Case Study: A 69-Year-Old Man with Multiple Myeloma

Mr. M is a 69-year-old man with refractory multiple myeloma who presented to the emergency department with fatigue, left hip pain, and severe nausea without vomiting. An abdominal and pelvic CT scan showed a left femur fracture, worsening myeloma lesions, and no evidence of bowel obstruction. Blood work revealed an elevated serum creatinine level of 2.1 mg/dL.

Mr. M reported being "stuck in bed" for a week due to left hip pain. He was prescribed oxycodone by his oncologist, which he took 5 mg every 4 hours around-the-clock with minimal relief. In between, he took ibuprofen 800 mg every 6 hours for additional pain control. He reported no bowel movement for 4 days. He was started on intravenous fluids and rotated to fentanyl via intravenous patient controlled analgesia (PCA) pump.

He was taken to the operating room for fracture, and, after an uncomplicated recovery, he was transferred to the floor with the fentanyl intravenous PCA. He continued to rate his nausea as moderate to severe. When assessed at bedside, he became tearful, stating he just found out from his oncologist that his multiple myeloma was unusually aggressive and that he likely only had 3 to 4 months to live—he had thought he had years. He stated he felt "sick to his stomach" when thinking about dying.

He described his nausea as wave-like and stated that he vomited once earlier in the day. He felt like when he used a rescue dose of the PCA, his nausea worsened. He also found that nausea increased with food. The medication administration record showed that he had received two prn doses of ondansetron 8 mg intravenously during the previous shift, which were not helpful. He had a bowel

Table 12.1 Tools to measure nausea and vomiting

Instrument	Type	Reliability/Validity
Visual Analog Scale (VAS)	100-mm line, with anchor descriptors at each end	Reliability is a strength.
Morrow Assessment of Nausea and Emesis (MANE) Rhodes Index of Nausea and Vomiting Form 2 (INV-2)	16 item, Likert scale (onset, severity–intensity) 8 item, Likert scale	Test/retest reliability 0.61–0.78 Split-half reliability 0.83–0.99 Cronbach's alpha 0.98 Construct validity 0.87
Functional Living Index Emesis (FLIE)	18 item, Likert scale	Content and criterion validity Internal consistency

Source: References 34, 39, 41, 42.

movement earlier, which improved his constipation. On physical exam, he was mildly cachectic, with diminished lung sounds, normoactive bowel sounds, and his surgical site was dressed clean, dry, and intact.

During interdisciplinary rounds, it was decided his nausea was likely multifactorial and exacerbated by his progressive disease, elevated creatinine levels, opioids, and anxiety. The team decided on a stepwise approach, starting oral olanzapine 2.5 mg nightly and intravenous metoclopramide 10 mg every 6 hours, which Mr. M felt was helpful in controlling his nausea. Though the fentanyl could have been contributing, Mr. M found the PCA most effective for his pain and finally felt like he could have some QOL. No changes were made to the analgesic regimen, with plans to reassess. Additionally, Mr. M was amenable to a chaplaincy consult and to receiving acupuncture.

Box 12.3 Classes of Antiemetics

Prokinetic agents
Dopamine receptor antagonists
Antihistaminic agents
Selective 5HT3 receptor antagonists
Corticosteroids
Benzodiazepines
Anticholinergic agents
Octreotide
Cannabinoids
Substance P antagonists (NK1 receptor antagonists)

Treatment of Nausea and Vomiting

Management of nausea and vomiting requires a combination of both pharmacological and nonpharmacological approaches. Understanding the cause(s) of nausea and vomiting is crucial as it allows proper selection of treatment regimens. Often the cause is multifactorial, requiring multiple interventions used concurrently. Investigations to rule out potentially reversible or treatable causes such as dehydration, electrolyte imbalances, and constipation should be considered.

Pharmacological Management of Nausea and Vomiting

It is essential for the nurse to know the clinical pharmacology of the large and increasing number of antiemetics available for use. This includes an understanding of nonoral routes of delivery. Medication delivery that does not require intravenous access is also frequently employed because patients with advanced illness may require control of severe symptoms in nonhospital settings.

Similar to the management of chronic pain, patients with chronic nausea will need around-the-clock medications for baseline symptom control, supplemented with rescue dosing. Guidelines for the pharmacological treatment of these symptoms in the palliative care population rely primarily on basic pharmacology and consensus guidelines, as multiple review articles have found the evidence base supporting pharmacological treatment of nausea and vomiting in advanced illness to be suffering from a lack of strong studies.[8,32,38]

Two approaches to pharmacological treatment have been described, a mechanistic approach and an empirical approach.[8,15,32] The mechanistic approach to treatment involves the selection of medications expected to block the relevant receptors in the emetic pathway as inferred from the patient's clinical presentation. For example, a prokinetic agent such as metoclopramide is chosen when a patient's nausea is related to gastric stasis. Once an appropriate medication is selected, it is titrated until the symptom is relieved, maximum doses are reached, or the patient experiences dose-limiting side effects. Classes of antiemetics are listed in Box 12.3. If the nausea is not relieved with the first agent, a second medication from another class should be added and similarly titrated.[15] Mechanism-based treatment is limited by pharmacologic and physiologic factors. Pharmacologically, the presence of similar receptors at multiple sites of the emetic pathway and the activity of single medications at multiple receptors prevent simple targeting of treatment. Physiologically, the etiology of chronic nausea and vomiting in advanced disease is often multifactorial or not known.[8]

The empirical approach for nausea and vomiting has been described as drug selection based on prescriber preference, or starting with one drug and adding or rotating to another if the first choice is unsuccessful.[15] Mechanistic and empirical approaches have resulted in similar response rates. Although the two methods have not been directly compared, both rely on a thorough understanding of the clinical pharmacology of the medications to be used.

Prokinetic Agents

Prokinetic agents include metoclopramide, domperidone, cisapride, and macrolide antibiotics. Domperidone and cisapride are recognized as effective prokinetic medications, but neither are available for use in the United States due to QTc prolongation and risk of serious cardiac toxicity.[8]

Prokinetic medications alleviate nausea and vomiting by stimulating motility of the upper GI tract. Four potential mechanisms for this effect have been proposed: stimulation of serotonin (5HT4) receptors in the gut wall, antagonism of 5HT3 receptors in the CTZ and gut, activation of motilin receptors, and release of the "dopaminergic brake" on gastric emptying. At higher doses, metoclopramide has antiemetic activity due to dopamine (D_2) receptor antagonism in the CTZ. Metoclopramide's activity at the 5HT4 receptor requires acetylcholine as a mediator at the myenteric plexus, thus, in theory, anticholinergic medications can antagonize its effect.[3,44]

Metoclopramide is widely used across palliative care settings and is often favored as first-line treatment of nausea and vomiting.[15,32] This prokinetic agent is specifically indicated in the setting of gastric stasis and is typically administered before meals. The central dopamine blockade in the CTZ results in a side-effect profile similar to antipsychotic medications, including extrapyramidal symptoms (EPS). Other adverse effects include akathisia, serotonin syndrome, and tardive dyskinesia. Due to the risk of tardive dyskinesia, a potentially irreversible condition, the US Food and Drug Administration (FDA) issued a black box warning. Risk is increased with use for greater than 12 weeks.[45] Reduced doses are recommended for patients with renal impairment and the elderly. Metoclopramide is contraindicated in the presence of complete bowel obstruction, GI hemorrhage or perforation, and immediately postoperatively.[38,45]

The macrolide antibiotic erythromycin has also been identified as a prokinetic medication due to its motilin receptor stimulation, and it has been shown to be effective in treating diabetic gastroparesis. Side effects include hepatotoxicity and QTc prolongation.[44]

Dopamine Receptor Antagonists: Butyrophenones, Phenothiazines, Atypical Antipsychotics

Butyrophenones

Droperidol and haloperidol are drugs in the butyrophenone class, acting primarily as dopamine antagonists. They achieve their antiemetic effect by binding to the D_2 receptors in the CTZ. There is mixed evidence regarding the use of haloperidol or droperidol for treatment of nausea and vomiting. To date, there have not been any randomized control trials (RCT) evaluating the effectiveness of these two drugs.[15]

Common side effects of this medication class include sedation, hypotension, anticholinergic effects, dystonias, EPS, QTc prolongation, and, rarely, neuroleptic malignant syndrome.[8,15,46] Haloperidol is less sedating than antipsychotics of the phenothiazine class. Because of its direct antidopaminergic activity, haloperidol should not be given to patients with Parkinson's disease. Additionally, it should be used cautiously with olanzapine as there is an increased risk for EPS.[2] The FDA has issued black box warnings for both drugs due to concerns related to prolonged QTc.

Citing its ability to treat nausea as well as delirium and hallucinations, researchers identified haloperidol as one of four essential drugs needed for quality care of the dying in an international survey of palliative care clinicians.[47] The sedating effect may be considered beneficial when caring for patients close to death. Dose reduction and caution with elderly patients is recommended for all dopamine antagonists.

Phenothiazines

Phenothiazines include prochlorperazine, chlorpromazine, and levomepromazine. Levomepromazine is not registered for use in the United States. These medications possess a broader spectrum of activity compared to haloperidol, blocking histaminic, muscarinic, serotonergic, and/or alpha-adrenergic receptors in addition to dopamine blockade.[48] No RCTs examining the use of levomepromazine to treat nausea and vomiting in palliative care were identified in a recent review.[49]

Their broad spectrum of activity is reflected in their numerous side effects including sedation, hypotension, anticholinergic effects, dystonias, EPS, QTc prolongation, leukopenia, and lowered seizure thresholds.[8,45] The availability of oral, rectal suppository, parenteral, and sustained-release formulations offers flexibility of administration in the outpatient setting, an important consideration in the palliative care population.

Atypical Antipsychotics

Olanzapine is an atypical antipsychotic that blocks dopaminergic, serotonergic, histaminic, and muscarinic receptors. Coverage of multiple receptors allows olanzapine to address nausea and vomiting that is caused by cancer or medications.[50] Consensus has shown that it has been used as a second-line antiemetic for patients with refractory nausea, with efficacy shown in small uncontrolled studies.[15,48,51] It has been used with advanced cancer patients in multicenter trials.[52] In small case reports, olanzapine was effective in treating nausea refractory to other treatments,[53,54] and reviews have identified RCTs showing its effectiveness for preventing and addressing breakthrough CINV.[55] Some authors have recommended olanzapine as a first-line monotherapy for nausea and vomiting in palliative care, though it can be included as part of multidrug regimens as well.[50]

Because advanced cancer patients may have multiple causes of nausea and vomiting (i.e., opioids, chemotherapy, disease burden), olanzapine is well suited for palliative care settings. Olanzapine causes fewer EPS than other antipsychotics and does not usually cause QTc prolongation. Its low cost and once-daily dosing schedule are additional benefits that can reduce financial and medication burden.[50]

Antihistaminic Agents

Antihistaminic agents include promethazine, cyclizine, meclizine, hydroxyzine, and diphenhydramine. Currently, cyclizine is not available for use in the United States. The first generation of piperazine antihistamines have recognized antiemetic properties related to H_1 receptor blockade in the vomiting center, CTZ, and vestibular nuclei.[3] Due to their action in the inner ear, antihistamines are specifically indicated for nausea and vomiting associated with movement, dizziness, or vertigo. Evidence supports antihistamines as a class likely to be beneficial for the treatment of nausea and vomiting in noncancer chronic diseases as well as postoperative nausea and vomiting, with less support for its use in CINV.[45] Diphenhydramine is often used in combination protocols to minimize the development of EPS when dopamine antagonists are used.[3,38]

Cyclizine is an H_1-antihistaminic anticholinergic medication. It achieves its antiemetic effect by decreasing excitability in the inner ear labyrinth, blocking conduction in the vestibular-cerebellar pathways, and directly inhibiting the H_1 receptor in the vomiting center. It is recommended for use when nausea or vomiting is caused by elevated ICP, motion sickness, pharyngeal stimulation, or mechanical bowel obstruction, and it is less sedating than promethazine.[3]

Antihistamines also have some anticholinergic activity, which can be beneficial when treating bowel obstruction. Cyclizine has greater anticholinergic activity than promethazine and is less sedating than scopolamine. Clinicians should be mindful that this same anticholinergic activity may reverse the effect of prokinetic drugs such as metoclopramide, and concurrent use should be limited. Other adverse effects include sedation, dizziness, headache, and lowered seizure threshold.[8,32]

Selective 5HT3 Receptor Antagonists

Serotonin antagonists include ondansetron, granisetron, tropisetron, dolasetron, and palonosetron and achieve their antiemetic effect by antagonizing 5HT3 receptors centrally in the CTZ and vomiting center and peripherally in the gut wall. There is strong evidence to support their use in the prevention of chemotherapy- and radiation-induced nausea and vomiting. Their effect is enhanced by the addition of dexamethasone and recommended by consensus guidelines.[2]

Consensus guidelines recommend their use for chemical causes of nausea and vomiting, vomiting refractory to dopamine antagonists, or when nausea is thought to result from massive release of serotonin from enterochromaffin cells, as seen in bowel obstruction and renal failure.[48] Due to their narrow mechanism of action compared with other antiemetics, the serotonin antagonists have a milder and more predictable side-effect profile, with constipation being the most common and significant side effect.[56]

Corticosteroids

Though the mechanism of action that produces the antiemetic effect is not well understood, there is strong evidence to support the use of corticosteroids, such as dexamethasone, in multidrug prophylactic antiemetic treatment during chemotherapy and radiation therapy.[45] Corticosteroids may be used to treat nausea stemming from increased ICP related to intracranial tumors, hypercalcemia of malignancy, or malignant bowel obstruction. Dexamethasone is thought to enhance the efficacy of 5HT3 receptor blockers, NK-1 blockers, and metoclopramide in the prevention of CINV.[45,48,57] Side effects are well documented, with significant adverse effects on nearly all organ systems, especially with long-term use. Short-term adverse effects include hyperglycemia, insomnia, and psychosis.[45]

Benzodiazepines

Benzodiazepines, such as lorazepam or alprazolam, act on the gamma-aminobutyric acid (GABA) receptors of the cerebral cortex and are often used to treat anticipatory nausea. Lorazepam may be used alone when the intent is to treat anticipatory nausea, due to its temporary amnestic effect, or when anxiety is a contributing factor to nausea or vomiting.[58–60] Sedation, confusion, and dizziness are possible common side effects. Benzodiazepines have been shown to be effective to treat anticipatory nausea in adult patients in combination with psychological techniques.[48,58–60]

Anticholinergic Agents

Anticholinergic medications include scopolamine, atropine, and hyoscyamine. Scopolamine (hyoscine) is the most commonly used anticholinergic medication for antiemesis and is a naturally occurring muscarinic antagonist. It achieves its antiemetic effect by blocking the muscarinic receptors in the vestibular nucleus and the vomiting center. A report of three cases of cancer-related nausea and vomiting found scopolamine to be effective when selected in a mechanism-based treatment plan.[61]

Anticholinergic medications are specifically indicated for nausea and vomiting associated with movement or dizziness and with treatment of bowel obstruction if the obstruction cannot be resolved.[61] These medications can cause the full range of anticholinergic side effects, including sedation, constipation, urinary retention, blurry vision, xerostomia, and delirium. Elderly patients are particularly sensitive to these side effects.[45] In the setting of imminent death, these anticholinergic properties are used advantageously to treat excessive respiratory secretions.[47] Anticholinergic medications are available in multiple formulations, including transdermal patches, ophthalmic drops that can be administered sublingually, and intravenous and subcutaneous injections, thus offering flexibility of administration in nonhospital settings.[45]

Somatostatin Analogues

Octreotide acetate is a long-acting somatostatin analog (vs. an antiemetic) that inhibits gastric, pancreatic, and intestinal secretions and reduces GI motility. Studies have shown octreotide may be helpful for nausea and vomiting associated with intestinal obstruction, where it is recommended to be used in conjunction with an antiemetic like haloperidol.[16] Additionally, it may be useful in cases where there is high-volume emesis.[62] Adverse effects may include diarrhea, abdominal pain, and nausea. Due to the cost of administration, somatostatin analogues are recommended only after a patient has tried standard treatments.[21] There are long-acting, depot forms of octreotide available for patients who would benefit from monthly dosing.

Cannabinoids

Marijuana is the best-known cannabinoid, and dronabinol is the plant extract preparation available for prescription use. The semisynthetic agents are nabilone and levonantradol. Cannabinoids are proposed to exert an antiemetic effect by binding to specific cannabinoid receptors in the brainstem and to the opioid mu receptor.[48,63] In one systematic review, nabilone was found to be superior to placebo, domperidone, and prochlorperazine for management of CINV, but not superior to metoclopramide or chlorpromazine. Another systematic review found oral nabilone, oral dronabinol, and intramuscular levonantradol were more effective treatments for CINV than dopamine antagonists, but were associated with significantly greater side effects.[48,63] Patients enrolled in various studies reported dizziness, dysphoria, euphoria, “feeling high,” and sedation as side effects to therapy.[64]

In recent years, there has been much attention focused on the medical use of cannabinoids, particularly for cancer symptom management.[63–65] Rigorous systematic reviews conclude that, based on limited evidence, cannabis-based medications may play a role in the management of CINV; however, ASCO, NCCN, and the Multinational Association for Supportive Care in Cancer and European Society for Medical Oncology (MASCC/ESMO) have not yet endorsed its use in standard guidelines.[5,63,64]

The evidence to support the use of cannabinoids in advanced cancer is weaker, and recommendations support the ongoing use of metoclopramide or haloperidol as first-line therapy, followed by 5HT3 receptor antagonists or olanzapine as second-line therapy.[63] With the approved use of cannabis-based medications for medical purposes, including cancer-related symptom management, more rigorous studies are needed to support its place in standard guidelines and to determine the risk–benefit ratio.

Substance P Antagonists (NK-1 Receptor Antagonists)

NK-1 receptor antagonists, such as aprepitant and fosaprepitant, prevent the binding of substance P to NK-1 receptors. Aprepitant is an oral drug that acts as an NK-1 antagonist, and its use in preventing and treating CINV has been strongly supported by national guidelines.[2,15,45,57] Aprepitant is particularly effective when combined with a 5HT3 receptor antagonist, such as ondansetron, and dexamethasone to prevent acute and delayed CINV.[5,57] Fosaprepitant is an FDA-approved, intravenously available NK-1 receptor antagonist that is converted to aprepitant within 30 minutes of administration. Studies comparing a single dose of fosaprepitant and a 3-day regimen of aprepitant showed similar outcomes in the prevention of CINV.[5]

NK-1 receptor antagonists are currently indicated for acute not chronic use, thus limiting their use for patients with advanced cancer who may not be receiving further disease-directed therapies.[45] Aprepitant is generally well tolerated, with some reports of nausea, diarrhea, and anorexia. Patients have reported pain at the injection site with fosaprepitant, as well as fatigue and hiccups.[45]

Combination Protocols

The use of multidrug regimens for the management of CINV is supported by a strong base of evidence including multiple RCTs and clinical practice guidelines. Regimens are stratified based on the emetic potential of the chemotherapeutic medications used and differ based on treatment of acute or delayed emesis.[2,5] The reader is encouraged to refer to current guidelines from NCCN,[2] ASCO,[66] and MASCC/ESMO.[16] Despite the availability of effective means of controlling CINV, nausea as an adverse event is not reliably assessed, nauseated patients often do not receive treatment, and adherence to guidelines is often compromised by the omission of dexamethasone.[53,67,68]

Home Hospice Approach to Selecting Antiemetics

In home hospice settings, routes of administration are an important consideration. Patients may or may not be able to take oral medications due to clinical decline or severity of nausea and vomiting. In these cases, sublingual medications may be a sound alternative. Other routes of administration, including rectal suppositories or subcutaneous injections, are more practical in home settings but require caregivers to be comfortable with administering medications via these routes. In the past, it was thought that topical combination gels of antiemetics, like ABR gel (Ativan, Benadryl, Reglan), had benefit in patients who could not take oral medications. However, studies have shown that these topical combinations lack evidence of efficacy, are not absorbed in any therapeutic manner, and are not recommended.[15,69,70]

Though the home hospice setting offers challenges for the management of nausea, vomiting, and other symptoms, consistent evaluation, intervention, and reevaluation will help address symptoms as disease progresses. The home setting may also be appropriate for inclusion of integrative modalities, like aromatherapy, massage, or acupressure.

Nonpharmacological Approach to Nausea and Vomiting

Despite the wide selection of pharmacological interventions with varying mechanisms of action, nausea and vomiting continues to be among some of the most distressing symptoms.[1,5] Although prophylactic antiemetic regimens have lowered the incidence of chemotherapy-induced vomiting from 90% to approximately 30% in patients receiving highly emetogenic regimens, nausea has been harder to control.[57] Additionally, anticipatory nausea and vomiting does not typically respond to commonly used antiemetic regimens.[59,60] Uncontrolled symptoms, whether treatment- or disease-related, possibly interfere with a patient's QOL and willingness to continue with treatments. Understanding nonpharmacological approaches to symptom management and integrating them into usual care is appropriate to minimize the physiological effects of uncontrolled symptoms and their potentially negative effects on QOL.

Nonpharmacological management of nausea and vomiting in addition to antiemetics has been tested over many years.[71] Treatments range from simple self-management techniques, integrative therapies, and, in some instances, palliative interventions to improve symptom management throughout disease treatment and at end of life. The use of certain nonpharmacological modalities has more recently been adopted into antiemetic guidelines, particularly for the treatment of anticipatory nausea and vomiting. Their use is based on a lower level of evidence, but with uniform consensus that the interventions are appropriate.[2,59,71]

Self-Management Techniques

Self-management emphasizes patient autonomy in their own care and encourages patients and families to assume the responsibility of managing their condition.[72] Self-management theories acknowledge the complexity of living with chronic conditions and the importance of managing these complexities in the context of one's everyday life rather than expecting patients to adhere to a series of prescribed orders that can be generalized across populations. These techniques start with evidence to guide treatment recommendations and are then tailored to meet the individual needs of patients and their families.[72,73]

There are a variety of potentially useful self-management strategies including psychological, cognitive, and behavioral modifications (Box 12.4[8,73,74]), and these should take into account individual factors, health status, and their environment when developing a plan of care.[74] While many of these interventions are not currently backed by strong evidence, they are associated with little harm and should be considered when treating nausea and vomiting in early and advanced disease.

Box 12.4 Self-Management Strategies for Management of Nausea and Vomiting

Dietary Modifications

Eat smaller, more frequent meals.

Reduce food aromas and other strong food odors.

Avoid spicy, fatty, and highly salty foods.

Premedicate with antiemetics prior to meals.

Give clear liquids.

Environmental Modifications

Avoid the sight and smell of food when not hungry.

Provide fresh air.

Avoid strong or unpleasant odors.

Minimize sights, sounds, or smells that can initiate nausea.

Psychological Strategies

Use relaxation and meditation.

Practice deep breathing.

Use cognitive distraction.

Other Strategies

Exercise.

Take medications as prescribed.

Source: References 8, 73, 74.

Integrative Medicine

There has been growing interest in the use of integrative medicine alongside curative and palliative treatments, with 38.3% of the US population estimated to use some form or combination of these techniques. This type of medicine refers to a wide variety of therapies that can be categorized into biological and nonbiological or behavioral interventions.[60,74–76] Recommendations are supported by limited data and suggest a role for integrative therapies for symptomatic relief of disease-related symptoms.[3,74,77,78]

There is enough evidence in the literature to support the implementation of certain techniques for prevention and treatment of nausea and vomiting; however, there is no convincing evidence favoring one method over another. Instead, the effectiveness of these techniques appears to depend on individual preference. RCTs are limited in number and sample size, stressing the urgent need for well-designed studies to test the effectiveness of particular interventions for managing adverse effects of chemotherapy and disease-related symptoms.[3,78,79] Patients should be educated to exercise caution before initiating certain herbal therapies due to the risk of drug interaction and adverse effects. The primary practitioner treating the patient's disease should be made aware of all conventional or integrative modalities of treatment.

Biological Therapies

Integrative biological therapies include nutritional supplements such as vitamins, minerals, botanicals, probiotics, and antioxidants as well as herbal medicines derived from natural sources. There have been few studies performed on these specific therapies for nausea and vomiting in advanced disease.[75,80]

An herbal remedy worth mentioning is ginger (*Zingiber officinale*), which is a spice best known for its role as a flavoring agent. Ginger has been used in Ayurvedic and traditional Chinese medicine to treat GI symptoms such as nausea and excessive flatulence since the sixteenth century. Studies have suggested ginger's efficacy in treating postoperative nausea, motion sickness, and pregnancy-associated nausea and vomiting through a combination of 5HT3, anti-inflammatory, and antispasmodic activities.[81,82] Newer studies have demonstrated the potential benefits of ginger in acute and delayed CINV in both the pediatric and adult populations, although findings and efficacy remain mixed.[81–84]

Reported adverse effects include grade two heartburn, bruising, flushing, and rash.[82] Potential adverse effects and herb–drug interactions must be understood before recommending ginger for symptom relief because the herb has been associated with increased risk of bleeding and hypoglycemia, and it is contraindicated with the use of tacrolimus, nonsteroidal anti-inflammatory drugs, blood thinners, and glucose-lowering medications.[85]

Nonbiological Therapies

Behavioral treatments that have specifically been recommended in guidelines for the treatment of anticipatory nausea and vomiting include progressive muscle relaxation, systematic desensitization, and hypnosis.[2,59] More detail will be paid to these particular interventions, as well as to acupuncture and acupressure later in the chapter. Other nonbiological integrative therapies are listed in Table 12.2.[74,86–91]

Acupuncture and Acupressure

Acupuncture is practiced in at least 78 countries, and its use, along with acupressure, for nausea and vomiting in the palliative care setting has been more widely explored when compared to other integrative therapies. Results have been mixed and integration into standards of care are limited by the lack of quality trials.[78,79]

Table 12.2 Nonbiological integrative therapies

Technique	Description	Comments
Music Therapy	Performed by credentialed professionals Incorporated at any phase of illness Addresses multiple dimensions of QOL First introduced in hospice population in 1980s	Likely to be effective Associated with significant reduction in severity and duration of CINV Perceived effects on autonomic nervous system Less time and energy to implement for patients No side effects
Aromatherapy	Therapeutic use of essential oils primarily via inhalation of its vapors	Oils such as peppermint and ginger have potential benefit of alleviating nausea and vomiting in postoperative and oncology patients Studies limited by design, small sample size, varied doses and methods
Massage	Soft tissue manipulation using touch and movement Reduces stress and anxiety while promoting relaxation which may lead to decreased heart rate, blood pressure, and respiratory rate	Effectiveness not established Variability in episodes of CINV and retching in breast cancer patients
Exercise	Any planned, structured, and repetitive bodily movement Incorporates cardiovascular, strength, and/or flexibility	Effectiveness not established in a study looking at female breast cancer patients receiving chemotherapy
Cognitive Distraction	Studied in adults and children Learn to divert attention away from a threatening situation and toward relaxing sensations Uses videos, games, puzzles, counting objects, deep breathing	No side effects Associated with decreased ANV and post chemotherapy distress

ANV, anticipatory nausea and vomiting; CINV, chemotherapy-induced nausea and vomiting; QOL, quality of life.

Source: References 74, 87–92.

Acupuncture is performed by trained specialists who insert fine needles or "studs" into acupoints along a specific meridian on the body. Acupressure can be performed independent of a practitioner and differs from acupuncture in that it involves applying digital pressure or acustimulation bands, rather than needles, on designated points on the body. These techniques are thought to work by stimulating or easing energy flow. More specifically in regards to nausea and vomiting, both acupuncture and acupressure use the P6 acupoint, which is most commonly used to alleviate symptoms and is located on the anterior surface of the forearm, approximately three finger-widths away from the wrist crease.[60,92]

Acupuncture and acupressure are nonpharmacological modalities that have been evaluated as "likely to be effective" for the prevention, management, and treatment of CINV when used in conjunction with pharmacological interventions.[60,79,92] A review of the current available literature favors the use of acupuncture in the different stages of CINV; however, some studies have shown no statistical difference when comparing acupressure to sham and control groups.[71,78] Despite the suggested benefits of acupuncture, the limited competency of practitioners to perform these techniques and limited availability of such practitioners has prevented increased use.[79] Acupressure offers a less invasive method to symptom management that may be effective and inexpensive.[92] The decision to integrate either or both interventions into the management of symptoms should be based on a holistic assessment of the patient's needs and goals.

Progressive Muscle Relaxation

Progressive muscle relaxation (PMR) allows individuals to respond to a stimulus that produces tension or anxiety by instead focusing on and isolating various muscle groups progressively up and down the body to induce relaxation.[60,74] This relaxation technique seems to be most effective in reducing the severity of nausea and vomiting after the administration of chemotherapy. PMR is not as effective with anticipatory nausea and vomiting unless used in conjunction with systematic desensitization or guided imagery.[60] In one study, the incidence of acute and delayed CINV was statistically lower for patients receiving PMR during the first 4 days following treatment, although no difference in severity of symptoms between groups was found.[74]

Systematic Desensitization

Commonly used to treat fears and phobias, systematic desensitization has proved particularly effective for treating anticipatory nausea and vomiting, as phobias may similarly develop through a learned-response or conditioning. The intervention works by teaching the patient how to counter a conditioned stimulus (e.g., entering the clinic, seeing the nurse) that normally elicits a maladaptive response (e.g., nausea and vomiting) with a response that is incompatible with feelings of nausea (e.g., PMR). Treatment has been documented as effective in more than half of treated patients.[60]

Hypnosis

While hypnosis was the first psychological technique used to treat and control anticipatory nausea and vomiting, very few controlled studies have been performed.[67] Hypnosis is a behavioral intervention that teaches patients to focus their attention on thoughts or images unrelated to the actual source of distress, often using passive types of muscle relaxation and distraction. Similar to systematic desensitization, patients learn to invoke a physiological state incompatible with nausea and vomiting. This technique has been effective mostly with children and adolescents because they may be more readily hypnotized. Overall, studies using hypnosis for anticipatory nausea and vomiting support the benefits of this intervention as it has no undesirable side effects and requires little training.[59,60,76]

Nursing Interventions

By definition, palliative care focuses on improving QOL and provides relief from distressing symptoms—which include nausea and vomiting.[93] The NCCN palliative care guidelines recommend aggressive symptom management, clarification of the intent of treatments, anticipation of the needs of patients and their families, and involvement of caregivers in the treatment process when appropriate.[2] Nurses have an essential role—whether it is doing an abdominal assessment at the bedside, providing antiemetic guidance over the phone, or asking about the pattern of a patient's nausea during an outpatient assessment. The palliative care nurse is instrumental in promoting a collaborative approach among team members. Nurses in various treatment settings should understand the standards of palliative care, advances in the management of nausea and vomiting, changes to relevant treatment guidelines, and potential side effects of treatments being administered.[94–96]

Just as vital are the roles that the patient and caregivers play in managing nausea and vomiting from disease or treatment. Oncology patients have reported high information needs regarding self-management of adverse effects.[74] As active participants in their care, they must be provided with the tools needed to practice symptom management and self-care. Personalized education plans and diaries with additional resources can help patients understand how to follow their plan at home and keep track of their symptoms—which can provide the healthcare provider with an understanding of symptom burden.[97,98] Education must include when and why to take certain antiemetic medications because patients may be given multiple agents, when to escalate symptom reporting to providers, and timelines for follow-up assessment.[99]

For CINV, acute phases are usually assessed and managed in the inpatient or outpatient setting; however, many patients are left to independently manage delayed nausea and vomiting, which can last up to 5 days post-treatment. Patients may be prevented from taking prescribed medications due to financial concerns, disbelief in treatment effectiveness, and perceived side effects, such as constipation or sedation. Likewise, certain patients may not report uncontrolled symptoms due to fear of being a "bad patient," communication issues with providers, or perceptions that symptoms are a normal part of cancer treatment.[50,97,100]

Sitting down with the patient to address his or her overall environment, fears, and concerns is crucial to ensure the steps to adequately control nausea and vomiting are achieved. Referring patients to other providers, such as palliative care specialists, should occur when symptoms cannot be controlled, or if additional support is needed.[99] Earlier involvement of palliative care resources can decrease symptom burden.

Conclusion

A major goal of palliative care is to improve QOL by addressing suffering in all its dimensions. It is important to remember that the most significant cost of inadequately controlled nausea and vomiting is patient suffering.[100] It can be difficult for nurses to meet the challenge of providing high-quality palliative care when there is a limited evidence base for interventions used routinely. Multiple studies and reviews have highlighted the need for more rigorous research on the management of nausea and vomiting, particularly in patients at the end of life and within the noncancer population. Nonetheless, vigilant assessment, appropriate use and evaluation of pharmacological and nonpharmacological interventions, and appropriate patient and family education and support may avert the need for unnecessary interventions at end of life and allow for QOL throughout the disease trajectory up until death and through bereavement. Nausea and vomiting profoundly affect all aspects of a person's well-being. Adequately managing these symptoms, especially at end of life, is essential.

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CHAPTER 13

Dysphagia, Hiccups, and Other Oral Symptoms

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Key Points

- Swallowing problems commonly occur in many advanced disease processes and can cause significant distress and burden on both the patient and the caregiver.
- Management of swallowing difficulties and oral complications in patients with serious illness focuses on preventing functional decline, maximizing quality of life and comfort, and supporting the patient's wishes.
- Oral symptoms and complications often occur concurrently and can impact patients' safety and comfort, as well as their ability to sustain nutrition and hydration and to manage oral medications.
- A multidisciplinary team approach will promote successful treatment with better outcomes and improved relief of symptoms.

Case Study: A Patient with Amyotrophic Lateral Sclerosis (ALS)

Mr. R was a 55-year-old man diagnosed with ALS. Two years prior, he developed weakness, twitching, and tingling sensation in his arms. He reported interval worsening in swallowing, speech, dyspnea on exertion and orthopnea, and loss of functional movements in his arms or hands. Mr. R received some relief from noninvasive ventilation consisting of BiPAP (bi-level positive airway pressure) several hours a day, although he struggled at night due to bouts of claustrophobia. Additional complications included worsening sialorrhea, laryngospasm, weak voice, poor cough strength, and fatigue with eating resulting in a 20-pound weight loss. He was given a home cough assist device and suction machine, and he was prescribed medications for anxiety and sialorrhea management. A videofluoroscopic swallow study with the speech-language pathologist (SLP) demonstrated that shakes and smoothies were the safest and most efficient consistency for his oral intake. The ALS team informed him that his clinical decline precluded him from feeding tube placement. Further family and team meetings were planned to assist the patient and family with decision-making.

Introduction

Food is a central aspect of life and also symbolizes love and community. Participating in the sharing of food and drink is a ritual that adds texture to life through socialization, communication, and enjoyment. Dysphagia, hiccups, and other oral symptoms such as sialorrhea, xerostomia, and dysgeusia are commonly experienced in patients with serious illnesses. These symptoms often occur concurrently, impacting not only a patient's safety and ability to sustain adequate nutrition and hydration, but also physical comfort, social well-being, and quality of life (QOL). The care and management of dysphagia and oral symptoms focuses on the specific disease process and trajectory while also encompassing the individual's preferences and goals.

Dysphagia

Definition

Dysphagia is defined as difficulty swallowing food or liquid. Swallowing impairments can threaten the safety and efficiency with which oral nutrition and hydration are maintained and patients' ability to manage oral medications. Chronic difficulty swallowing can be both frustrating and frightening for patients and their families. Because nutrition is compromised, generalized weakness, diminished appetite, weight loss, or malnutrition may ensue. Aspiration can occur, causing pneumonia, fevers, malaise, shortness of breath, and death.[1–3]

The psychological impact of dysphagia cannot be overstated. Its development may be pivotal in redirecting care from sustaining life to a palliative focus.[1] Swallowing difficulties and withdrawal from daily activities such as eating and drinking may become increasingly prevalent and alter social encounters.[2] Managing tube feedings, care of a gastrostomy stoma, or changing diet textures may become a significant burden. The challenge in managing dysphagia in patients with serious illness is to advocate for alignment with patient's goals of care, reduction in symptom burden, and maximization of QOL, even at the risk of optimal nutrition and hydration.

Physiology and Pathophysiology of Swallowing

Understanding the physiology of normal and aberrant swallowing is critical to meeting the challenge of caring for the patient with dysphagia. Swallowing, an extremely complex physiological act, involves the passage of food or liquid from the oral cavity through the esophagus and into the stomach, where the process of digestion begins.[3,4] Swallowing requires exquisite timing and coordination of more than 30 pairs of muscles under both voluntary and involuntary nervous system control within the brainstem as well as feedback from sensory receptors. Because humans swallow hundreds of times per day and are largely unaware of the activity, it is remarkable that difficulties do not occur more frequently.

The act of swallowing takes less than 20 seconds from the moment of propulsion of the bolus from the mouth into the pharynx until the bolus reaches the stomach. For purposes of discussion, the act of swallowing is divided into three stages: the oral stage, the pharyngeal stage, and the esophageal stage (Figure 13.1). In reality, these stages do not occur discretely; rather, there is melding and overlapping of events. Difficulty swallowing can occur anywhere along the swallowing continuum depending on the underlying disease.[5]

The first stage of swallowing (see Figure 13.1), the oral stage, is responsible for readying the bolus (ball of food or liquid) for swallowing.[6,7] Bolus preparation is under voluntary control and can be halted or changed at any point depending on the consistency and size of the food bolus. It is also during this stage that one takes pleasure from the flavor and texture of food through the chemoreceptors of the tongue and palate. During the oral stage, the bolus is partitioned into smaller portions. Sensory receptors assist in mediating saliva production, which is critical to moisten the bolus and assist with forming an optimal consistency.[3]

The tongue gathers all the food particles, and once the bolus is formed it is propelled backward into the pharynx by contraction of the tongue and floor of mouth muscles. Inefficient bolus flow may result from weakness in the tongue-driving force on the bolus from surgical tongue resection. Loss of control, reduced oral or lingual sensation, or impaired movement results in the bolus entering the airway while it is open, trouble containing the bolus in the oral cavity, and/or pocketed food remaining in the oral cavity.

The soft palate elevates to prevent material from entering the nasal passage. If the velopharynx is not sealed, nasal regurgitation of liquids and particles of solids occurs, such as in palate cancer where treatment involves resection and in patients with progressive neuromuscular disease.

The second stage of swallowing, the pharyngeal stage (see Figure 13.1), lasts approximately 1 second. This stage is the most complex, requiring precise timing and coordination between respiration, airway protection, bolus propulsion, and opening of the cervical esophagus. A carefully sequenced pattern of events is controlled by the central swallowing center in the medulla. Sensory feedback continually modulates and fine-tunes the motor response. If this sensory feedback loop is disrupted, the onset of the pharyngeal swallow may be delayed or, in severe cases, absent.[4,6,7]

The bolus is moved through the pharynx by pressure generated from the base of the tongue contacting the pharyngeal walls via pharyngeal muscles that progressively contract and relax and by

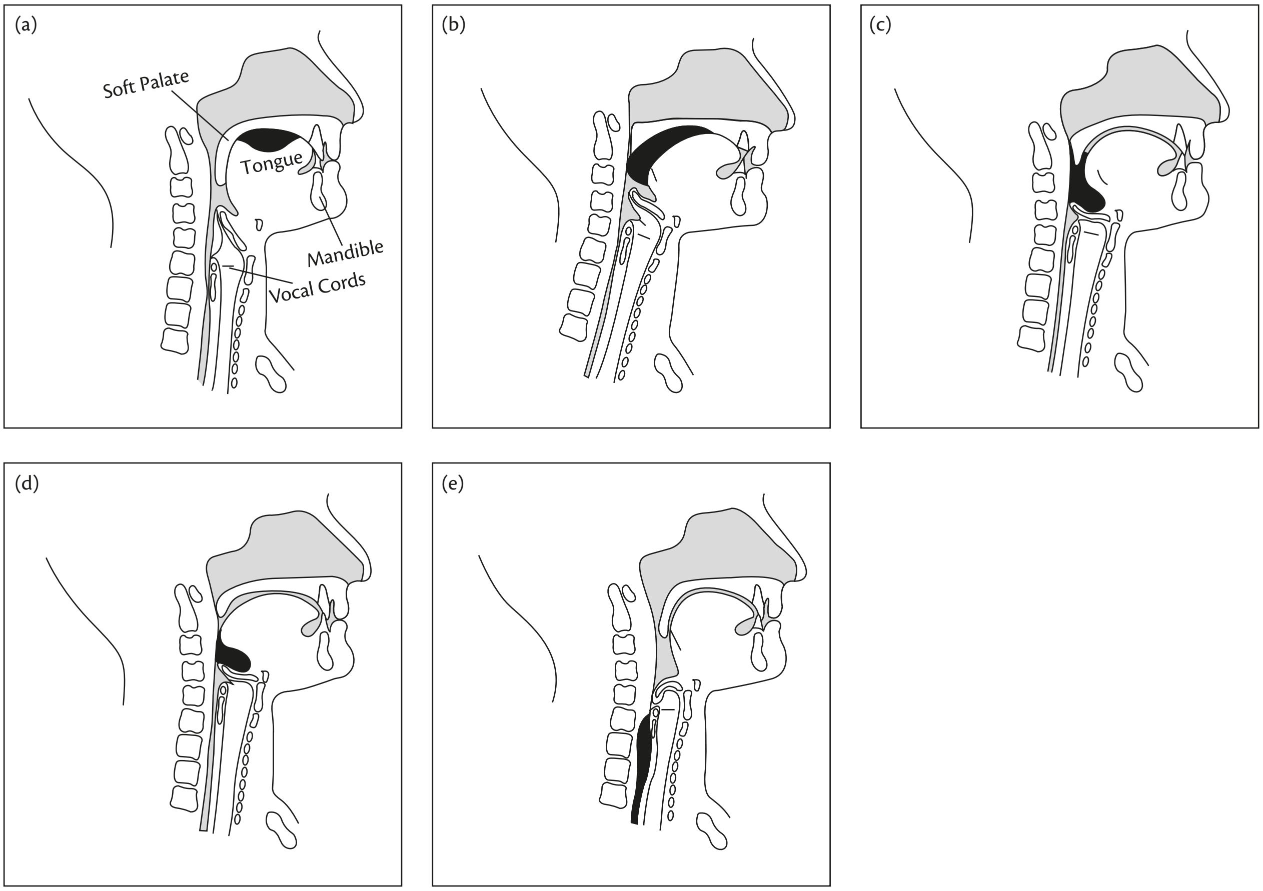

Figure 13.1 Stages of swallowing, beginning with voluntary initiation of the swallow by the tongue (A), oral transit (B), pharyngeal swallowing with airway protection (C) and (D), and esophageal stage (E).

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relaxation of the upper esophageal sphincter. Weakness in pharyngeal muscles, obstruction from a mass, surgical alterations, or fibrotic tissue can all result in impaired propulsion of material through the pharynx and into the esophagus.

The upper esophageal sphincter (UES) separates the pharynx from the esophagus and is closed at rest. It prevents air from entering the esophagus and prevents esophageal contents from re-entering back up into the pharynx.[8] The UES opening creates a negative pressure in the esophagus, helping to propel the bolus through the pharynx and toward the esophagus.[8,9] Incomplete relaxation of the UES results in residue in the pharynx and, if abundant, material may spill over into the unprotected larynx and trachea.[9]

The process of airway protection, or closure of the larynx, is critical to prevent aspiration not only during oropharyngeal swallowing but also during periods of gastroesophageal reflux, regurgitation, or emesis. Breathing momentarily ceases during swallowing, and laryngeal closure expels any material that may have entered the laryngeal vestibule and prevents further material from entering the airway.[3] The bolus must fully clear the pharynx before the airway reopens or else this material may fall into the open airway and be aspirated.[3,4,6] Incomplete or delayed laryngeal closure due to mistiming or muscular incompetence may result in aspiration. Reduced sensory function and weakened laryngeal musculature may impair airway protection if the cough mechanism is weak and ineffective.

The esophageal stage of swallowing (see Figure 13.1) is the longest phase and involves transport of the bolus from the upper esophageal segment, through the lower esophageal segment, and into the stomach.[4,10] Like the pharyngeal phase of swallowing, the esophageal stage is under involuntary neuromuscular control. However, the speed of propagation of the bolus is much slower, with a rate of 3–4 cm/sec compared to 12 cm/sec in the pharynx.[11]

As the bolus reaches the esophagus, contractile waves carry the bolus through to the lower esophageal sphincter and into the stomach.[6,8,9] The lower esophageal sphincter contracts to its resting, closed state to contain the gastric contents within the stomach.[10,11] Dysfunction in the esophagus may result from reduced propulsion, and irregular or absent contractions. Narrowing of the esophagus from strictures or obstruction from a mass, as may occur in esophageal cancer, can limit the passage of the bolus through the esophagus and into the stomach.

Case Study: A Patient with Dementia and Strokes

Ms. T is an 85-year-old woman with a history of late dementia. She was admitted to the hospital with an acute stroke that affected her right side and her ability to walk, communicate, and swallow. During a swallowing assessment, Ms. T displayed inconsistent periods of wakefulness, oral and lingual weakness, and a weak cough. A swallowing trial revealed inability to clear the bolus from her mouth, latent onset of a swallow response, and a wet cough. She was deemed at increased risk for aspiration, pneumonia, dehydration, and malnutrition. A family meeting was convened to discuss the best treatment plan consistent with her goals of care.

Ms. T's advance directive stated, "no extraordinary or life-prolonging measures such as a breathing machine or stomach tubes." The family agreed to focus on comfort and forego any other aggressive medical care, including medically administered nutrition and hydration. A decision was made to move forward with oral feedings, small amounts of soft food items, and sips of liquid during periods of wakefulness and interest in eating. The family acknowledged the inherent risks of pulmonary infection, dehydration, and malnutrition. Prior to Ms. T's discharge home with hospice, the SLP, the nurse, and the dietician collaborated with the family and discussed the safest feeding techniques, strategies to improve the taste and texture of food, and oral care.

Etiology of Dysphagia

Dysphagia is a common symptom in patients receiving palliative care. Swallowing difficulties may be the presenting clinical feature or a sign of disease progression or advancing illness. Understanding the physiological impact of the illness is critical in evaluation of the swallowing disorder and the method of management. Some commonly encountered etiological categories in palliative care are discussed here.

Neoplasms

Brain Tumors

Although not often a presenting symptom, swallowing problems can develop directly or indirectly as a brain tumor increases in size and compresses surrounding structures. When extrinsic tumors are located around the brainstem or in the skull base, compressing or invading the lower medulla, the swallowing center may be directly affected. Other neoplasms can directly invade cranial nerves that innervate the swallowing structures. In addition to direct tumor effects, swallowing may be affected by surgical resection, chemotherapy or radiation side effects, depressed levels of consciousness, reduced awareness, fatigue, depression, seizures, and overall functional decline in 85% of patients.[12–14] High-grade tumors result in greater symptom burden such as seizures, altered consciousness, progressive cognitive deficits, and difficulty swallowing in the end-of-life phase.[15] Dysphagia may impact the patient's ability to take essential oral medications, including antiseizure or corticosteroid medications for tumor edema.

Head and Neck Cancer

Cancers of the head and neck arise in the oral cavity, tongue, oropharynx, larynx, nasopharynx, and sinuses. A high percentage of patients experience dysphagia, if not in the acute stage of the disease and its treatment, then as a late radiation therapy toxicity. The prevalence of aspiration and aspiration pneumonia in this population is substantial.[16]

Treatment approaches include surgery and chemoradiotherapy, depending on the cell type, location, tumor size, and presence of neck metastases. Complex surgical resections irrevocably alter the normal biomechanics of oropharyngeal swallow physiology, such as in the case of a glossectomy or mandibulectomy.[17] Laryngectomy, or removal of the voice box, offered to patients with advanced laryngeal cancer, results in a permanent stoma in the neck, altering the normal mechanism of swallowing, voice, and breathing.

Over the past twenty-five years, "organ preservation" using chemoradiation therapy has been the primary approach for treating cancers of the pharynx and larynx with the goal of sparing the organs involved in speech and swallowing. Unfortunately, "organ preservation" is not synonymous with "functional preservation." In spite of advances in radiotherapy methods aimed at sparing normal tissue and the use of targeted chemotherapy agents, patients suffer from significant acute treatment toxicities including pulmonary aspiration, mucositis, edema, xerostomia, and trismus (restricted jaw opening). Late radiation effects, occurring years after treatment, may include cranial neuropathies and fibrosis which can impair airway protection, pharyngeal contraction and bolus drive, and opening of the upper esophagus, resulting in chronic, progressive dysphagia and silent aspiration.[18–21] Some patients require feeding tubes years after treatment because of recurrent pneumonias and weight loss.[22]

Malignant Esophageal Tumors

Esophageal carcinoma can arise either from squamous cells of the mucosa or as adenocarcinomas of the columnar lining of Barrett's epithelium. Tumors of the squamous cell type are generally located in the upper or mid-esophagus, with smoking and alcohol consumption as high-risk factors, while tumors of the adenocarcinoma type are located more distally and occur in those with gastroesophageal reflux and obesity.[23]

If diagnosed early, endoscopic treatments such as radiofrequency ablation or endoscopic mucosal resection (EMR) or surgical esophagectomy may be the recommended treatment. Chemotherapy and radiation therapy may also be used either following surgery or as a concomitant treatment.[24] In cases of advanced disease, symptomatic relief of dysphagia and pain is typically the focus and may be best accomplished with least complications by brachytherapy or placement of a wire mesh self-expanding stent to open the lumen of the esophagus.[23,25] Treatments such as external beam radiotherapy and chemotherapy are associated with considerable side effects resulting in painful, difficult swallowing and in esophagitis, mucositis, xerostomia, loss of taste, and lymphedema.

Non–Head and Neck Cancer

Oncology patients often develop transient or persistent oropharyngeal dysphagia in a wide variety of cancers due to tumor location, side effects of radiation, cytotoxic effects of chemotherapy, cancer-related weakness and fatigue, and neurologic or respiratory compromise.[26,27] Chemotherapy and radiation therapy to the thoracic region may cause toxicity to the oral, pharyngeal, and/or esophageal mucosa, such as esophagitis and/or mucositis.[18,20,21] This results in altered taste, pain, reduced appetite, nausea, mucosal bleeding, and formation of lesions such as herpes simplex virus or varicella zoster.[28] Although the prevention of weight loss is of utmost importance for improved QOL and improved outcomes, this is not always possible especially if the patient is experiencing dysphagia.[29]

Progressive Neuromuscular Diseases

Motor Neuron Disease

Motor neuron disease (MND), of which the most common disease is Amyotrophic Lateral Sclerosis (ALS), is encountered with unfortunate regularity in patients receiving palliative care. ALS begins in the central nervous system (CNS), and rapidly progressive symptoms involve the upper and lower motor neurons.[30,31] One-quarter of ALS patients initially present with swallowing difficulty, with many displaying distal weakness that travels proximally to involve the bulbar musculature. Respiratory failure is the usual cause of death in patients with ALS because of weakness in diaphragmatic, laryngeal, and lingual function.[30,31]

As patients experience lingual, oral, pharyngeal, and respiratory muscle weakness, they develop increasing difficulty and fatigue with eating. Frequent choking may occur, and weight loss has a significant impact on QOL. Many patients reach a point where the burden of eating outweighs the pleasure, and alternative non-oral nutrition should be discussed early in treatment. An important prognostic factor is forced vital capacity (FVC), or the amount of air one can exhale after taking a maximal inhalation, which should ideally be greater than 50% at the time of PEG insertion for optimal benefit.

New pharmacological agents are being introduced to slow progression of the disease, treat symptoms, and prolong life as much as possible, including riluzole, a glutamate antagonist.[30,32–34] In 2010, the US Food and Drug Administration (FDA) approved dextromethorphan and quinidine (Nuedexta). Originally prescribed to alleviate pseudobulbar symptoms, it was found to palliate other bulbar symptoms including speech, swallowing, and saliva management. At the time of this writing, more extensive studies, including a phase III trial, are needed to confirm results and determine the duration of the treatment effect and impact on disease progression.[35] Edaravone (Radicava) is another medication for patients with ALS, approved by the FDA in 2017.[36]

Parkinson's Disease and Parkinsonian Syndromes

Parkinson's disease (PD) is a relatively common, slowly progressive disease of the CNS marked by an inability to execute learned motor skills automatically and resulting in resting tremor, bradykinesia (slowness of movement) and rigidity, gait dysfunction, autonomic disturbances, sleep problems, mood disorders, and cognitive dysfunction.[37] Dysphagia in PD may occur from changes in striated muscles under dopaminergic control and in smooth muscles under autonomic control.[31] Delayed swallow response, rigidity of musculature (lingual, laryngeal), reduced muscle strength, and incomplete opening of the upper esophageal sphincter can be present and contribute to aspiration.[31,38] Dysphagia and resultant pneumonia is one of the most prevalent causes of death in patients with Parkinson's disease.[33,38,39]

There is a paucity of research on clinical practices for dysphagia in patients with PD, although several reviews have demonstrated little positive effect of medical and surgical treatments on swallowing physiology.[39] Early identification, treatment focused on specific physiologic impairments and exercise-based therapies (see later section on swallowing exercises), and changing bolus characteristics may have a positive impact on swallowing function.[39]

Two other progressive neuromuscular diseases associated with dysphagia include progressive supranuclear palsy (PSP) and multiple system atrophy (MSA). Patients with PSP do not respond as well as patients with PD to pharmacological treatment. Instead, they display earlier clinical symptoms of dysphagia, and thus their dysphagia may be more aggressive and more life-threatening. One study correlated the initial development of pneumonia with a survival time of within 2.3 years. Dysphagia-related death accounted for 91% of deaths in studied patients with PSP.[40]

Although not nearly as common as PD, MSA is a rapidly progressive neurodegenerative disorder characterized by parkinsonism, ataxia, pyramidal signs such as spasticity, and autonomic failure such as urinary dysfunction and orthostatic hypotension, with a median duration from onset to death of almost 10 years.[41] There are two subtypes based on predominant clinical features: cerebellar (MSA-C) and parkinsonism (MSA-P). Dysphagia onset occurs within 5 years after diagnosis with MSA-P (the parkinsonian subtype).[41]

Myopathies

Myopathy is a neuromuscular disorder that results in muscle weakness and can be either inherited or acquired. Muscle disorders, or muscular dystrophy, are chronic and progressive, resulting in weakness of oral, pharyngeal, and esophageal muscles as well as in the muscles involved in breathing and walking.[42] Oculopharyngeal muscular dystrophy (OPMD) is an autosomal dominant muscle disorder with hallmark features of a slowly progressive ptosis and dysphagia, proximal limb and facial weakness, and abnormal gait, with onset generally occurring after age 40.[42]

Other chronic muscle diseases that are often associated with dysphagia include inclusion body myositis (IBM) and advanced Duchenne muscular dystrophy (DMD). Muscle wasting and loss of tongue and oromotor strength is a common feature that leads to oropharyngeal dysphagia, including smaller bolus size, reduced swallowing efficiency, nasal regurgitation, and reduced upper esophageal opening.[43] Laryngeal dysfunction, reduced cough strength, and impaired muscles of respiration are also factors that predispose these patients to reduced airway clearance and aspiration.[43] There is currently a lack of evidence from randomized controlled studies on best interventions for dysphagia in muscle disease.[43]

Multiple Sclerosis

Multiple sclerosis (MS) is characterized by scattered, multifocal plaques of demyelination within the CNS that result in varying combinations of motor, sensory, and cognitive deficits. Symptoms that affect QOL include fatigue, spasticity, paroxysmal symptoms, pain, ataxia, bladder and bowel dysfunction, depression, cognitive problems, and dysphagia.[44] Swallowing dysfunction largely depends on the location of the lesions. Dysphagia occurs in more than one-third of MS patients, typically at the end stage, and appears to be more common in those with brainstem or cerebellar involvement and in those with greater neurologic impairment.[44] Sclerosed plaques can be found in the cortex and the brainstem and can affect cranial nerves, affecting coordination of the swallowing sequence and/or sensation. Disease-modifying medications may slow the progression of disability by reducing inflammation in the CNS, the frequency and severity of MS attacks, and symptom burden. Thus, early initiation of drug treatment and ongoing medication management is recommended.[45]

Dementia

Dementia encompasses many etiologies; however, the most common form is Alzheimer's disease. Symptoms of dementia include progressive memory loss, poor awareness, loss of language abilities, inactivity, agitation, and confusion.[46] The different types of dementia and their varying trajectories result in an unspecific dysphagia. However, common attributes include the inability to independently self-feed and an inability to focus for the duration of meal times. With disease progression, patients may not engage in the task of eating and swallowing at all. They may hold food in their mouth for prolonged periods without mastication or bolus formation, especially with uniformly textured foods such as pureed items or bland foods. This often occurs when a swallowing dyspraxia makes it hard to plan and coordinate motor movements. Decreased consciousness and sedation predispose patients to both food and liquid aspiration. Additionally, sensory impairments and lack of attention reduce the ability to control the bolus in the mouth, resulting in aspiration from premature spillage before the pharyngeal swallow has been elicited. Moreover, behaviors such as distraction or agitation may prolong feeding time and hence reduce the amount of nutrition and hydration received.[47]

One study revealed that the most common clinical complications in patients at the end-stage of Alzheimer's disease were eating problems (86%), febrile episodes (53%), and pneumonia (41%), and these are associated with poor prognosis and high mortality rates.[46] Swallowing and feeding difficulties that arise in the late stages of dementia are irreversible, although treating concomitant infections, metabolic disarray, and/or dehydration may result in improved functioning.[47–49]

There is growing consensus that in cases of advanced and late-stage dementia, a palliative care approach focusing on maximizing oral intake and reducing treatment burden is appropriate. Studies indicate that hand-feeding is at least as good as tube-feeding for the outcomes of death, aspiration pneumonia, functional status, and patient comfort, while tube-feeding is associated with agitation, increased use of physical and chemical restraints, and worsening pressure ulcers.[48] The American Academy of Hospice and Palliative Medicine's *Choosing Wisely* campaign states that feeding tubes in patients with advanced dementia are not recommended and emphasizes assisted feeding by hand for comfort and human interaction.[50]

Aging, Chronic Illness, and Frailty

Aging, sarcopenia (muscle loss associated with aging), and multisystemic chronic illnesses can result in extreme muscle wasting and poor functioning. These diseases include end-stage chronic obstructive pulmonary disease, coronary artery disease, heart failure, and chronic renal failure.[51,52] Frailty, a state of increased vulnerability resulting from aging-associated decline in reserve and function across multiple physiologic systems, can contribute to sarcopenia and low physiologic reserve. Sarcopenic dysphagia, or difficulty swallowing due to the loss of muscle mass and strength of skeletal muscles, can impair tissue elasticity in the tongue and pharynx.[53–55] Additionally, aging affects the larynx; specifically, the vocal folds may not close sufficiently or timely enough to protect the airway.[55–57] Sensorimotor changes may occur that impact salivary production, taste, and smell. Swallowing efficiency in elderly adults is also affected by delayed swallow response.[55–57] The reduction in functional reserve leaves older individuals highly vulnerable to insults to the swallowing system for which they may be unable to compensate. Oropharyngeal dysphagia in the elderly has been estimated at 30–40% in community dwellers, rising to as much as 60% in institutionalized older adults.[51]

Hospitalized medical patients with cachexia, loss of muscle mass, significantly compromised pulmonary systems, and general weakness and deconditioning due to lengthy hospitalizations often develop dysphagia.[53,58] In a fragile and immunocompromised condition, there is a higher risk of pulmonary infections, poor outcomes from aspiration, and fatigue, all of which impact the ability to sustain appropriate nutrition. Moreover, this population is prone to negative outcomes from dysphagia, including increased length of hospital stay and greater risk of mortality.[58] Difficulty in completing oral care due to a low level of consciousness and/or the presence of an endotracheal tube can promote colonization of oral bacteria in the hospitalized patient. If aspiration of colonized oropharyngeal contents occurs (secretions, vomitus, food/liquid mixed with colonized secretions), it can result in aspiration pneumonia.[59] General immobility further impairs spontaneous pulmonary clearance, resulting in an inability to expectorate aspirated material.

Dysphagia as a Side Effect of Medications

There are 160 known medications with dysphagia specified as a potential adverse effect. Medications should be reviewed to determine if they produce dysphagia either as a possible side effect or through other mechanisms, including direct action on the CNS; as a by-product of reduced levels of consciousness, oral dryness, or taste disturbances; through reduced coordination or motor function; and/or when there is direct insult to esophageal mucosa and tissue injury that affects gastrointestinal (GI) motility.[26,60–62] (See Table 13.1.)

Table 13.1 Dysphagia as a side effect from medications

Drugs that affect the smooth and striated muscles of the esophagus	Anticholinergics, antimuscarine agents
Drugs that cause dry mouth/xerostomia	Antipsychotics, angiotensin-converting enzyme (ACE) inhibitors, antiemetics, antihistamines, diuretics, antidepressants, anticholinergics
Drugs that induce CNS depression	Benzodiazepines, opioids, antiepileptics, muscle relaxants, anticonvulsants
Drugs that cause esophageal mucosal injury	Bronchodilators, nonsteroidal anti-inflammatory meds, anticholinergics, antibiotics

Source: References 60, 61.

Role of the Speech-Language Pathologist

Speech-language pathologists (SLP) are expert specialists in the assessment and management of oropharyngeal dysphagia. SLP involvement has been shown to have a positive effect in both prevention and treatment of oropharyngeal dysphagia.[63] An SLP skilled in palliative care can provide education about the swallowing process and the impact of disease progression, evaluate empirical data to determine swallowing potential and trajectory, assist in decision-making, and guide families and caregivers in safe feeding methods.[1] The SLP must carefully weigh the benefits of any intervention with its burden, attend to the individual spiritual and emotional issues, display skills and knowledge in biomedical ethics and legal issues, and remain highly sensitive to the psychosocial and family ramifications of treatment recommendations.[64,65] (See Chapter 56 for further discussion of the role of physical and occupational therapy in palliative care decision-making.)

Assessment of Dysphagia

For the patient with a serious and life-limiting illness, the goals of the swallowing evaluation are to (1) identify the underlying physiological nature of the disorder, (2) determine reversible conditions that may be a causative or contributing factor,[66] (3) determine interventions that can best alleviate the dysphagia and concomitant distress, and (4) collaborate with the patient, family, and caregivers on the safest and most efficacious method of nutrition and hydration. There are numerous tests and procedures that can be undertaken to evaluate swallowing function. The correct evaluation is driven by the specific patient complaints and concerns and goals of care.

Clinical Examination of Swallowing

Eliciting a description of the patient's complaints about swallowing, current eating habits, appetite, and diet is critical to understanding the physiological basis of the problem. Details of disease progression and prognosis and consideration of a patient's level of alertness, positioning, breathing, and ability to follow directions are also considered when determining the aggressiveness of a swallowing work-up and its treatment.

Direct observation of the patient eating, drinking, or taking medications by a perceptive clinician can yield valuable information about the underlying disorder. The SLP is vigilant for indications of chewing inefficiencies, aspiration, difficulties managing secretions, or obstruction. Typically, the SLP assesses the patient's oral-motor and sensory function as well as level of arousal, cognitive communicative abilities, and respiratory status while observing the partaking of a variety of liquid and solid foods (e.g., semi-solid, soft solid, and, where appropriate, food requiring mastication). Speech and voice are analyzed to assist in understanding the underlying physiology of the swallowing disorder. Functional airway protection is a critical predictor of safe swallowing and thus an important element of the swallowing evaluation. Although this cannot be definitively discerned from clinical observation alone, patients who have weak voices and decreased respiratory force for coughing and pulmonary clearance are at risk for pulmonary compromise.

Since aspiration may be silent in up to 40% of patients with dysphagia (e.g., present with no overt sign or symptom that material has entered into the airway, such as a cough or throat clear),[67] close attention is paid to occult signs of aspiration, including wet vocal quality, frequent throat clearing, delayed coughing, and changes in breathing.[4] Silent aspiration can only be confirmed definitively with an instrumental examination.

Screening of Swallowing Function

Given the causes for dysphagia and its impact on patients' overall health, outcomes, hospital length of stay, and cost of care,[58] early identification of swallowing dysfunction in high-risk hospitalized patients is paramount.[67,68] Dysphagia screening has been formally recognized in the care of stroke patients for more than a decade.[69] The use of a formal, validated screening protocol to identify potential aspiration risk can be completed by the nurse or a member of the healthcare team who undergoes appropriate training to assist in determining if a patient is safe to start eating and drinking. Screening programs have been shown to improve patient outcomes, including a 55% reduction in cases of pneumonia and a shorter hospital length of stay in many hospitalized patient populations.[58]

Specific clinical predictors (e.g., abnormal volitional cough, dysphonia, slurred speech),[70] subjective dysphagia symptoms, and patient reports[71] have been shown to accurately predict the increased risk of swallowing dysfunction and aspiration that warrants further instrumental swallowing evaluation (see Box 13.1).

Instrumental Evaluation

An instrumental swallow evaluation may be clinically indicated to delineate swallowing physiology and can provide valuable information for management, assess for integrity of the swallowing anatomy and mucosa, determine effectiveness of swallowing strategies, and clarify or confirm aspiration risk. Instrumental or objective evaluations take many forms (see Table 13.2) and are driven by the patient's complaints and suspected etiology.[72,73]

Box 13.1 Indications of a Swallowing Disorder

Reduced alertness or cognitive impairment

Coma, heavy sedation, dementia, delirium
Inattention during eating
Residual food in the oral cavity after eating
Impulsivity with regard to eating
Playing with food

Signs of oral-pharyngeal dysfunction

Dysarthria or slurred, imprecise speech
Wet sounding voice
Inability to manage secretions
Drooling or leaking from the lips
Frequent throat clearing, coughing or choking during or immediately after meals
Voice changes after swallowing
Laborious chewing, multiple swallows per small bites
Residual food in the oral cavity after eating
Nasal regurgitation
Recurrent aspiration pneumonias
Food or fluid noted in tracheotomy tube
Changes in posture or head movements during eating

Signs of esophageal dysfunction

Regurgitation or emesis after swallowing
Sour taste in mouth after eating
Solids caught in the chest region
Burping during/after eating
Pain on swallowing

Specific patient complaints (adapted from the EAT-10)

Sensation of food caught in the throat
Coughing and choking while eating
Painful or effortful swallowing
Alterations in attitudes toward eating
Swallowing problem interferes with pleasure when eating or socializing
Shortness of breath while chewing or after meals
Weight loss
Protracted meal times or inability to complete a meal
Avoidance of particular foods or fluids
Refusal to eat in the presence of others

Source: References 3, 4, 26, 28, 70, 71.

Management of Dysphagia

The physiologic information obtained from clinical and instrumental swallowing assessment facilitates determination of intervention strategies aimed at increasing swallowing safety and efficiency and/or maximizing residual abilities. Often, treatment uses a variety of approaches and techniques simultaneously. Management strategies are individualized and only effective when targeting specific impairments in the biomechanics of swallowing as determined by an objective swallowing evaluation. Consideration of any swallowing intervention should be aligned closely with overall goals of care and treatment plan. When the disease process shifts to the terminal stage, and/or when swallowing function declines, swallowing interventions and recommendations shift as well to focus on maintaining comfort, minimizing symptoms, and upholding the patient's wishes.

Exercise-Based Therapy

Swallowing interventions may include active strengthening exercises and rehabilitation aimed at directly improving or maintaining swallowing function and the biomechanics of swallowing. Exercises may target increasing tongue strength or movement,[4,75] pharyngeal contraction, airway and vocal fold closure, hyolaryngeal excursion, and opening of the UES. Respiratory muscle strength training (RMST), although not a direct swallowing exercise, targets inspiratory and expiratory muscles for improved cough, voice, and swallow function.[76] Using a small handheld device, resistance training can be incorporated into the SLP dysphagia management program and has been shown to be effective for patients with ALS, Parkinson's, and stroke.[76]

Like any other strengthening program, exercises are only beneficial in certain instances, such as when muscle strength is impaired and can be improved; must be individualized to the specific dysfunction; and must consider principles of exercise physiology to determine appropriateness. The effectiveness and appropriateness of direct swallowing intervention in a patient with a degenerative process, such as dementia-related cognitive impairment, or with advanced stages of disease may be questionable.[31] Therefore, it is imperative to determine the realistic impact and the appropriate implementation of a course of swallowing exercises.

Compensatory Swallowing Strategies

Alterations in head and neck posture, modifications in food and liquid texture, techniques to improve airway closure, and external cueing to increase sensory awareness and feeding behaviors are considered compensatory in nature. Their effectiveness may be limited in patients with altered cognition, pulmonary complications, or who do not have available a caregiver who can assist them. Other modifications, such as altering food/liquid consistency, may significantly impact patient's pleasure with eating.

Postural Modifications

Postural changes during swallowing often have the effect of diverting the food or liquid to prevent aspiration or obstruction but do not change the swallowing physiology.[3,4] These strategies may be used in isolation or in combination, depending on the nature of the underlying swallowing pathophysiology (see Table 13.3).

Table 13.2 Instrumental Swallowing Evaluation Methods

Instrumental Evaluation	Primary Anatomic Focus	Description	Clinical Indications/Role
Videofluoroscopic Swallowing Study (VFSS) or Modified Barium Swallow (MBS)	Oropharynx; upper esophageal screen	A dynamic radiographic study Completed by a speech-language pathologist and radiologist Patient positioned upright while ingesting a variety of consistencies of barium-coated liquids and foods (pureed, semisolids, and solids) in controlled volumes	Assess oropharyngeal swallowing anatomy and physiology Screen the proximal esophagus Determine the nature of swallowing impairment Evaluate the integrity of airway protection Identify the presence and etiology of aspiration Assess the effectiveness of behavioral maneuvers and bolus texture modifications that may decrease the risk of aspiration and increase swallowing efficiency
Fiberoptic Endoscopic Evaluation of Swallowing (FEES)	Oropharynx and larynx	Endoscopic evaluation A thin, flexible nasoendoscope with a small distal camera is passed transnasally and into the pharynx Patient swallows saliva, food, and liquid dyed with food coloring Performed at the bedside or in a clinic setting	Determine the presence of laryngeal penetration, aspiration, and pharyngeal retention View laryngeal and pharyngeal anatomy Assess sensory integrity of the pharynx and /or larynx Evaluate effectiveness of compensatory swallowing strategies such as postural modifications or swallowing maneuvers Provide visual feedback to the patient during treatment
Barium Swallow and Upper GI Study	Esophagus, stomach, duodenum	Conducted under radiography Patient positioned upright and in the supine position Patient ingests liquid barium, and in some cases, a barium tablet and baking soda crystals	Identify mucosal and anatomical abnormalities, such as esophageal strictures, tumors, hiatal hernias Assess esophageal motility
Esophagogastroduodenoscopy (EGD)	Entire upper GI tract	Endoscopic evaluation using a thin, flexible tube passed intraorally through the esophagus and into the stomach Completed by a gastroenterologist	View the lining of the esophagus, stomach, and upper small intestine (duodenum) Confirm the presence of strictures and mucosal anomalies, hiatal hernias, tumors, or bleeding Obtain tissue biopsy Perform interventional procedures such as dilation and/or stenting of the esophagus, banding of varices, and removal of foreign bodies
High resolution manometry (HRM)	Pharynx, UES, esophagus through to the LES	A thin catheter with pressure monitors is introduced through the nostril into the throat, esophagus and stomach May include dry swallows (without food/liquid), small water bolus, and food substance such as pudding Completed by a gastroenterologist or speech pathologist (pharyngeal manometry)	Assess motility of the esophagus and the function and relaxation of the lower esophageal sphincter (LES); hallmark features of achalasia Can be used to assess pharyngeal contraction and relaxation of UES peristalsis Obtain pressure readings to measure the strength (“vigor”) and pattern of muscle contractions and intrabolus pressure
pH Probe	Esophagus	Ambulatory 24-hour pH probe A small tube with a pH sensor at the tip is passed through the nose into the esophagus Collects data on a portable or wireless monitor	Determine the presence and amount of reflux disease, or GERD and heartburn Measure acid exposure in the esophagus and compares results to “normal” Considered the gold standard test for acid reflux

Source: References 4, 40, 72, 73, 74.

Changes in Texture and Consistency of Food

Changes in food texture and liquid consistency may play a vital role when managing dysphagia and may be the best option to ensure a patient’s comfort or improve safety or efficiency of oral intake (see Table 13.4). However, these alterations can be unappealing and may necessitate emotional adjustment and support for patients. Typically, this management strategy is reserved for patients who are unable to follow directions to use postural changes or for whom other compensatory strategies or exercises are not feasible.[4] Enhancing the bolus characteristics to include more texture can

Table 13.3 Postural modifications

Postural Strategy	Rationale
Chin tuck	Closes larynx, pushes tongue closer to posterior pharyngeal wall, and promotes epiglottic deflection
Head back	Promotes bolus movement through the oral cavity with assistance of gravity
Head tilt to stronger side	Directs bolus down stronger side with assistance of gravity
Head turned to weaker side	Diverts bolus away from weaker side of pharynx, promotes opening of upper esophagus
Head tilt plus chin tuck	Directs bolus down stronger side while increasing closure of larynx
Head rotation plus chin tuck	Diverts bolus away from weaker side while facilitating closure of laryngeal vestibule and vocal folds

Source: Adapted from References 3, 4.

sometimes induce mastication and bolus formation more readily than a bolus that is both flavorless and homogenous in texture. This is particularly evident in patients with advanced dementia. (See Box 13.2 for suggestions for oral feeding.)

Specialized commercial agents derived from modified food starch or gum-based ingredients (xanthan, guar, cellulose) can be used to thicken liquids. Gum-based thickeners are preferred due to their better taste and improved performance over starch-based thickeners in terms of stability over time and at varying temperatures.[77] Thickened liquids release the fluid in the gastrointestinal tract and do not alter the body's absorption rate of fluids, although they may promote dehydration.[78] This can stem from patients lacking motivation to drink thickened fluids and thickened fluids providing the sensation of being full, as well as the increased fiber content of gum-based thickeners impacting early satiety.[78]

In an attempt to standardize the terminology surrounding stages of food and liquid consistency, the International Dysphagia Diet Standardisation Initiative convened a task force in 2015 with a goal to improve patient safety and improve cooperation and collaboration among healthcare professionals.[79] The classification system uses 7 levels of thickness, from 0 for thin liquids up to 7 for regular solid foods, and it measures thickness by either a fork-drip test or a syringe flow test for the viscosity of liquids.[79] At the time of this writing, this classification scale has not yet been widely adopted.

A close partnership and collaboration with the registered dietician will ensure the best outcome.[80–81] Nutritionists can provide individualized suggestions for calorie-dense foods or high-calorie nutritional supplements, depending on the patient's metabolic status. Food preparation in a manner that increases caloric and nutritional value and maximizes hydration is helpful, such as using cream, oil, and butter; adding sauces to foods, and increasing high-calorie healthy items such as hummus and avocado. Additionally, some nutritional supplement drinks are thicker liquids and calorically fortified, providing a safer alternative to more solid consistencies, while others come in a pudding format. Listed in Box 13.3 are cookbooks specific for patients with swallowing problems.

Airway Clearance Techniques

The ability to effectively cough to clear secretions and aspirated material is essential to reduce pulmonary infections and respiratory difficulties. Supportive airway clearance techniques may be

Table 13.4 Diet modifications for patients with dysphagia

Diet	Definition	Example	Indication - IDDSI
Liquid: Nectar consistency (Level 2)	Mildly thickened liquid.	Similar in viscosity to tomato juice; less thick than honey consistency	Reduced liquid bolus control Delayed swallow initiation and airway closure
Liquid: Honey consistency (Level 3)	Moderately thickened liquid.	Similar in viscosity to honey; available in ready-to-serve packaging or use thickening agent	Reduced oral or lingual control of liquid bolus Delayed swallow initiation and airway closure
Pureed diet (Level 4)	Blenderized food with added liquid to form smooth homogenous consistency. No chewing necessary.	Applesauce, yogurt, moist mashed potatoes, puddings	Significantly reduced chewing Reduced alertness or awareness of oral bolus Impaired pharyngeal contraction, esophageal stricture
Minced diet (Level 5)	Ground, finely chopped or diced foods that easily form a cohesive bolus with minimal chewing.	Pasta, soft scrambled eggs, cottage cheese, ground meats	Some limited chewing possible; may be protracted or laborious
Soft, moist, bite-sized diet (Level 6)	Naturally soft foods requiring some chewing. Food is cut in small pieces; serve with gravy to moisten.	Soft meats, canned fruits, baked fish Avoid raw vegetables, bread, nuts, and tough meats	Reduced endurance for prolonged meal Reduced attention span Tongue/lip weakness

Source: Adapted from: Reference 79, http://iddsi.org/framework.

Box 13.2 Suggestions for Oral Feeding

1. *Remove distractions at mealtime*. This can help patients focus on swallowing and using compensatory swallowing strategies.
2. *Emphasize heightened awareness of sensory and taste cues*. Using a larger bolus size, increased downward pressure of the spoon on the tongue, and cold or sour foods may alert the patient that food is in the mouth and improve oral sensation and awareness.
3. *Provide feeding utensils*. Patients with hand tremors or weakness that impact self-feeding may be aided with devices such as weighted cuffs or built-up utensils.
4. *Optimize the position of the patient*. Sitting as upright as possible when eating, drinking, or taking medications is typically deemed safest. Reduce the tendency to slump forward or to the side, or head extension, which can make the patient more vulnerable to aspiration.
5. *Schedule meal times*. Time meals to coincide with increased function and reduced fatigue or sedation from medications.
6. *Consider more frequent, smaller meals with high-calorie supplements*. Increased frequency of small meals may help patients who do not have sufficient efficiency or endurance to complete an entire meal at one time.
7. *Encourage the maximal number of calories for the least amount of effort*. Make every bite count with increased caloric and nutritional value by using cream, oils, and butter; adding sauces, and avoiding calorie-free beverages or foods unless otherwise indicated.
8. *Consider hand-feeding when appropriate*. Hand-feeding allows for continued intimate contact between patient and caregiver.

Box 13.3 Cookbooks for Altered Food Consistency Diets

- *Safe Swallowing with Dysphagia: A Puree Cookbook for Dysphagia-Related Lifestyles*. Sharon Lynn Mercer and Andrew Grachuk. CreateSpace Independent Publishing Platform, 2015.
- *Gourmet Puree Recipes: The Ultimate Collection*. Daniel Tyler. Encore Publishing, 2013
- *Down Easy: A Cookbook for Those with Swallowing Difficulties*. Judith M. Best. Judy Best Cookx. 2012.
- *Soft Foods for Easier Eating*. Sandra Woodruff, MS, RD, LDN and Leah Gilbert-Henderson, PhD, LDN. Square One Publishers, 2010.
- *Eat Well-Stay Nourished: A Recipe and Resources Guide for Coping with Eating Challenges. Vol 2*. SPOHNC: Support for People with Oral and Head and Neck Cancer, 2013.
- *Easy-to-Swallow, Easy-to-Chew Cookbook: Over 150 Tasty and Nutritious Recipes for People Who Have Difficulty Swallowing*. Donna Weihoffen, JoAnne Robbins, Paula Sullivan. John Wiley & Sons, Inc., 2002.
- *The Dysphagia Cookbook*. Elayne Achilles. Cumberland House Publishing, 2004
- *The I-Can't-Chew Cookbook*. J. Randy Wilson and Mark A. Piper. Hunter House, Inc. Publishers, 2003.

recommended to improve oxygenation and cough function, mobilize secretions in order to combat pulmonary infection, improve swallowing, and strengthen airway clearance. These techniques have been found to reduce length of time on a ventilator, reduce intensive care unit (ICU) stays, resolve atelectasis/consolidation, and/or improve respiratory mechanics.[82] These supportive treatments can be beneficial as part of the armamentarium of dysphagia management in patients with aspiration risk and/or poor secretion management.

A mechanical insufflator-exsufflator (MIE), or cough assist machine, provides positive pressure to maximally inflate the lungs, followed by an abrupt switch to negative pressure. The rapid change from positive to negative pressure simulates a cough, thereby assisting sputum clearance, and this can prevent pneumonia and other complications associated with secretion retention.[82,83] The device can be used with an oral mouthpiece as well as via tracheostomy tube.

Mucus clearance devices such as an Acapella or flutter valve are small handheld devices that are simple and inexpensive and that create the resistive features of positive expiratory pressure (PEP) and vibrations to help mobilize secretions. They allow more air to enter the airways, thus increasing the pressure behind secretions in order to move them toward the larger airways where they can be more easily expelled.[84] As the patient breathes out, mucus is loosened so that it is easier to cough up, promoting healthier lungs and airways. These devices may be an alternative to chest physiotherapy, suctioning alone, and manual cough assist. A therapist skilled in these techniques, typically a respiratory therapist or physical therapist, can assess the patient to determine the best technique. The American Association for Respiratory Care (AARC) offers a clinical guideline for the selection of an appropriate device.[82]

Medically Administered Hydration and Nutrition

For patients with a disease process that results in dysphagia and an inability to swallow, a decision often needs to be made regarding the best route to provide alimentation with consideration of medically administered hydration and nutrition. (See Chapter 15 for further discussion of medically administered hydration and nutrition.) While aspiration of food or liquid could realistically evolve into a life-threatening respiratory illness, paradoxically, committing a patient to non-oral feeding (also known as "non per os [NPO]")[7] is also fraught with complications and ethical dilemmas, especially in a patient with a life-limiting disease process. Real or perceived medical benefits, such as improved nutrition and hydration, easier administration of medications, and diminished pain and suffering are weighed against adverse side effects and impact on QOL. Irrespective of the scenario, the following should be considered:

1. Families and patients should be informed about the risks and consequences of developing aspiration pneumonia and malnutrition and the benefits and risks of non-oral and oral feeding options in order to make fully informed decisions and to guide decisions.[48,85]
2. A growing body of literature shows that, overall, there are limited medical benefits of medically administered hydration and nutrition in improving survival rates, reducing aspiration risk, and improving functional status and that the expected benefits may exceed actual outcomes.[86–88]
3. The presence of a feeding tube does not inherently imply NPO, or nothing by mouth. Some patients may continue to take food or liquid for their pleasure and comfort.

Medication Administration for Patients with Dysphagia

Oral medications can present enormous challenges to patients with swallowing difficulties. One study focusing on patients with chronic dysphagia found that more than 60% of subjects had difficulty swallowing tablets.[89] The physiologic difficulties they experienced included multiple swallows to clear the pill, residue in the pharynx after swallowing, increased time needed to swallow pills, use of liquid to assist in washing the pill down, and airway compromise.[89] Difficulty swallowing may impact adherence to medication regimens, result in missed medications or medication errors,[90] and alter the effectiveness of medical treatment, necessitating alternative modes of administration and modifications. A pharmacist's review of medications and formulations is essential[91] and suggestions may include:

1. Discontinue medications that are nonessential or no longer indicated.
2. Seek alternative routes of administration (transdermal, buccal, rectal, or intravenous).
3. Change to a liquid form when possible. Crush or cut pills, open capsules, or bury the tablets and pills whole in a semi-solid food such as applesauce, pudding, yogurt, or ice cream to create a uniform consistency. Crushing, opening, or chewing a medicine can alter pharmacologic properties, impact safety or efficacy (such as with opioid analgesics), and may result in a potentially toxic and lethal dose.[90,91]
4. Try compounding, performed by a pharmacist, to create an alternative form such as a powder, nebulized substances, liquid, lozenge, or suppository tailored to the specialized needs of an individual patient.[91]
5. Orally disintegrating medication (ODT) technology has been used to formulate medications that rapidly disintegrate in the oral cavity once placed on or under the tongue. Healthcare providers and patients should refer to the FDA for guidance found at their website.[92]

Hiccups

Case Study: A Woman with End-Stage Liver Disease and Hiccups

AL is a 55-year-old woman with cirrhotic liver failure, admitted to the hospital with worsening abdominal discomfort and ascites. The medical team informed her that, due to multiple comorbidities, transplant was not an option. The same day, AL developed hiccups that affected her ability to talk, eat, and sleep. A thorough examination was performed to determine the etiology. AL was prescribed metoclopramide to decrease abdominal distention and lactulose to relieve constipation. Paracentesis was performed to remove four liters of fluid from AL's abdomen, but the hiccups persisted. She was later prescribed baclofen 10 mg three times daily, which reduced the severity of the hiccups. However, as AL's ascites returned, the hiccups became more severe. The medical team recommended placement of a peritoneal drain to provide ongoing relief of ascites and better manage the distention causing AL's hiccups. Following drain placement, AL was discharged with home hospice services.

Definition and Impact

Hiccup, or singultus, is defined as sudden, involuntary contractions of the diaphragm and intercostal muscles, terminated by an abrupt closure of the glottis, producing a characteristic sound of "hic." Hiccup frequency is between 4 and 60 times per minute.[93] Although seemingly insignificant, hiccups can negatively impact QOL.[93,94] Prolonged hiccups may cause fatigue, insomnia, anxiety, depression, and weight loss.[93,95] While there are little data regarding the incidence of hiccups in the overall population, estimated prevalence in cancer patients is 3.9–4.8%.[96]

Pathophysiology of Hiccups

Hiccups arise from a synchronous spasmodic contraction of the diaphragm and the intercostal muscles, which results in sudden inspiration and prompt closure of the glottis, causing the hiccup sound. Anatomically, hiccups are generated by a reflex arc, which is made up of an afferent limb, a reflex center, and an efferent limb that stimulates muscular contraction.[93,97] Afferent impulses travel to the reflex center via the vagal and phrenic nerves, as well as T6–T12 sympathetic fibers. The reflex center, although not fully identified, is believed to include parts of the hypothalamus, the brainstem, and the cervical spinal cord. Efferent impulses leaving the reflex center utilize the vagal and phrenic nerves to stimulate areas of the diaphragm, intercostal muscles, and glottis, thereby producing the contractions known as a hiccup.

The precise physiologic function of hiccups is not well understood. There are several proposed theories, including the possibility that hiccups are a primitive intrauterine reflex to prevent fetal aspiration of amniotic fluid, a remnant of gill ventilation from a prior phase of human evolution, or—because hiccups are frequent during fetal development—a mechanism to prepare for independent respiration outside the womb.[97] There appears to be an inverse relationship between partial pressure of carbon dioxide (pCO_2) and hiccups; that is, an increased pCO_2 decreases the frequency of hiccups and a decreased pCO_2 increases frequency of hiccups.[93,97] Hiccups have a minimal effect on ventilation and are likely not a respiratory reflex.[97] Still, frequent or intense hiccups may cause significant fatigue and the sensation of labored breathing.

Hiccups are divided into three categories: benign, persistent, and intractable. Benign, self-limiting hiccups occur frequently, with episodes lasting from several minutes to 2 days. Gastric distention is the primary etiology. Other causes include spicy foods, alcohol ingestion, excess smoking, and psychogenic factors, particularly if they cause excitement or hyperventilation.[98] Persistent, or chronic, hiccups continue for more than 48 hours but less than 1 month. Hiccups continuing for longer than a month are considered intractable.[93,95] In palliative care, the duration of hiccups may not be as important as their perceived impact on the particular patient population. For instance, an obtunded patient with advanced liver disease may not be bothered by hiccups, while a patient with chronic obstructive pulmonary disease (COPD) may experience greater distress due to overall weakness and breathing that is already impaired at baseline.

There are more than 100 documented potential causes of intractable hiccups, although many have little supporting evidence outside of individual case reports.[93,98] Etiologies may be structural, metabolic, inflammatory, or infectious disorders. Structural causes affect the peripheral branches of the phrenic and vagal nerves, as in abdominal or mediastinal tumor compression, as well as in CNS disorders such as stroke, brain tumors, and neurologic diseases.[97,98] Other common causes of hiccups in terminal illness include sepsis and metabolic imbalances; pericarditis, myocardial infarction, pneumonia, or pleuritis; and gastrointestinal conditions such as esophagitis, gastric distension, gastritis, pancreatitis, and hepatitis.[93]

Many medications may trigger hiccups, including steroids, chemotherapeutic agents, dopamine antagonists, megestrol, methyldopa, opioids, benzodiazepines, and muscle relaxants.[98] Dexamethasone, frequently used as a palliative medication for cancer patients, has been shown to cause hiccups.[95,99] Substances such as alcohol, nicotine, and recreational drugs are other common causes.

Assessment of Hiccups

In palliative care, extensive workup for hiccups is impractical, uncomfortable, and rarely useful in determining etiology or delineating treatment. There is little evidence that laboratory tests are helpful in determining optimal management.[99] Thus, assessment includes a subjective review of the distress induced by the hiccups. Patients may experience secondary symptoms such as anorexia due to impaired swallowing, shortness of breath from the inability to take deep breaths, fatigue as a result of excess energy use, insomnia from hiccuping all night, heartburn from acid reflux produced by hiccups, and depression as well as the worry that hiccups are untreatable.[93]

Objective assessment includes the history and duration of the hiccups, previous episodes, and interference with rest, eating, or daily routines. Inquiry into possible triggers may be helpful, including patterns during the day and activities preceding the hiccups such as eating, drinking, or positioning. A review of recent trauma, surgery, procedures, and acute illness may reveal underlying causes for the hiccups. Finally, a thorough medication history may be useful in identifying pharmacologic triggers.

The presence of hiccups themselves is quite apparent. Further physical exam may assist in ruling out other underlying health conditions or signs of a septic process. Oral inspection may reveal swelling or obstruction. Any wounds or infections should be examined, and a thorough respiratory assessment should be performed.[93] More specifically, evaluate for temporal artery tenderness, foreign bodies in the ear, throat infection, goiter, pneumonia or pericarditis, abdominal distention or ascites, and signs of stroke or delirium.[93,98,99]

When supported by a patient's goals of care, specific testing may be warranted to eliminate other causes of hiccups. Chest x-ray may rule out pulmonary or mediastinal processes as well as phrenic/vagal irritation from peri-tumor edema in the abdominal area.[93,97] Blood work, including a complete blood count and metabolic panel, may exclude infection, electrolyte imbalances, and renal failure.[93,97] A computerized tomography (CT) scan of the abdomen or head may be done to preclude abnormalities or hemorrhage.[93,97]

Management of Hiccups

The absence of larger randomized controlled trials has resulted in lack of consensus around treatment,[99] leading to specialty-specific treatment modalities that favor familiar medications. Consequently, management is based on previous individual successes rather than a systematic, evidence-based approach. Treatment for hiccups should focus on the underlying disease. Both nonpharmacological and pharmacological interventions may be used. Therapies include physical maneuvers, medications, and other procedures that interfere with the hiccup arc.[99]

Nonpharmacological Interventions

Nonpharmacological treatments are divided into seven categories and include respiratory measures, nasal and pharyngeal stimulation, vagal stimulation, psychiatric treatments, gastric distention relief, phrenic nerve disruption, and other miscellaneous treatments. They are outlined in Box 13.4.

Box 13.4 Nonpharmacological Interventions for Hiccups

Respiratory measures

Breath holding
Rebreathing in a paper bag
Diaphragm compression
Ice application in mouth
Induction of sneeze or cough with spices or inhalants

Nasal and pharyngeal stimulation

Nose pressure
Stimulant inhalation
Tongue traction
Drinking from far side of glass
Swallowing sugar
Eating soft bread
Soft touch to palate with cotton-tipped applicator
Lemon wedge with bitters

Vagal stimulation

Ocular compression
Digital rectal massage
Carotid massage

Psychiatric treatments

Behavioral techniques
Distraction

Gastric distention relief

Fasting
Nasogastric tube to relieve abdominal distention
Lavage
Induction of vomiting

Phrenic nerve disruption

Anesthetic block
Phrenic block
Suboccipital release traction and posterior neck pressure

Miscellaneous treatments

Bilateral radial artery compression
Peppermint water to relax lower esophagus
Acupuncture

Source: References 93, 108.

Pharmacological Interventions

Initial pharmacologic therapy should attempt to decrease gastric distention, the common cause in 95% of cases. Additional measures include hastening gastric emptying and relaxing the diaphragm with simethicone and metoclopramide. If ineffective, second-line therapy should focus on suppression of the hiccup reflex.[93,97,98] Common pharmacological interventions are listed in Table 13.5. However, there is little evidence as to which interventions are most effective.

Table 13.5 Suggested pharmacological interventions for hiccups

Agent	Effect
Agents to decrease gastric distention	
Simethicone 4–125 mg PO q6h	Promotes gastric emptying
Metoclopramide 10–20 mg PO/IV q4–6h	Promotes gastric emptying
Muscle relaxants	
Baclofen 5–10 mg PO tid	Acts at synaptic level
Midazolam 5–10 mg liquid PO q4h	Reduces muscles spasm
Anticonvulsants	
Gabapentin 300–600 mg PO tid	Inhibits calcium channels that control neurotransmitter release in the brain and spinal cord
Pregabalin 25 mg bid	Same mechanism as above
Carbamazepine 600–1,200 mg PO bid-tid	Reduces muscle spasm
Valproic acid 15 mg/kg/day PO in one to three divided doses. May increase by 250 mg/wk until hiccups stop	Reduces muscle spasm
Phenytoin 200 mg IV × 1, then 100 mg PO qid	Reduces muscle spasm
Antidepressants	
Amitriptyline 10–50 mg/day PO	Acts at central nervous system
Sertraline 50–150 mg/day PO	Acts at central nervous system
Corticosteroids	
Dexamethasone 40 mg/day PO	Reduces inflammation
Dopamine agonists	
Haloperidol 2–10 mg PO/IV/SQ q4–12h	Reduces muscle spasm
Chlorpromazine 5–50 mg PO/IM/IV q4–8h or 25–50 mg IV in 1 L 0.9% normal saline	Blocks dopamine and alpha adrenergic receptors
Calcium channel blockers	
Lidocaine 1 mg/kg IV loading dose followed by infusion of 2 mg/min	Blocks sodium channels
Nifedipine 10–80 mg/day PO	Causes vasodilation to suppress spasm
Other medications	
Ketamine 0.4 mg/kg	Acts on cortex and limbic system
Amitriptyline 25–90 mg/day PO	Inhibits serotonin and norepinephrine uptake

Source: References 93, 99, 108.

Nursing Interventions for Hiccups

Although hiccups appear to be a simple reflex, their specific mechanism of action is often unclear. Many patients express frustration that the discomfort and disruption caused by hiccups is not taken seriously. Nursing interventions should focus on providing information about the broad range of strategies used to eliminate hiccups.

The extent of treatment for hiccups will depend on the degree of distress and the impact that hiccups have on the patient's daily routine, sleep, and nutrition. Nonpharmacological interventions should be considered first, including respiratory maneuvers, nasal and pharyngeal stimulation, distraction, and peppermint water. If these measures fail to eradicate the hiccups, pharmacologic interventions should be suggested. While any single agent may be ineffective, combined therapies target several regions that trigger hiccups and are more likely to produce relief.

If medications fail to relieve hiccups, the nurse should suggest a referral to a pain management specialist in order to explore interventional treatment options. These may include phrenic or cervical nerve blocks[93,97] or radiofrequency ablation.[97]As always, discussion with the patient should include prognosis and the benefits and burdens of any procedure. If hiccups become extremely burdensome and other therapies have failed, sedation may be considered. For further discussion of palliative sedation, the reader is referred to Chapter 27.

Other Oral Symptoms

Case Study: A Patient with Oral Symptoms

Mr. T is a 50-year-old man with newly diagnosed oropharyngeal cancer. He was treated with a 6-week course of concurrent chemoradiation. Prior to his treatment, he underwent a videofluoroscopic study to assess swallowing function and was provided with prophylactic exercises to maintain his baseline swallowing ability. Following treatment week 2, Mr. T began to experience mucositis/oral inflammation, resulting in thick mucus that was difficult to clear because of worsening dysphagia. A strategy of expectorating secretions and using a portable suction device was implemented. Further oral symptoms included odynophagia (oral pain), xerostomia (dry mouth), and dysgeusia (altered taste). Pain management consisted of opioids, topical lidocaine, and soothing mouthwash. In an effort to combat dry mouth and taste alterations, Mr. T used sugar-free hard candies, artificial saliva spray, and regular tooth brushing prior to meals. Despite these interventions, Mr. T's appetite was very poor, and he began to lose weight, so a feeding tube was placed. He continued to swallow small amounts of liquids as able. Although chemoradiation therapy ended at 6 weeks, the treatment-related toxicities continued to escalate for several more weeks before slowly subsiding.

Oral Symptoms in Serious Illness

Oral symptoms are common in palliative care patients. The overall condition of teeth, lips, gums, and oral mucosa directly affects a patient's ability to swallow, manage secretions, eat, drink, and communicate. Oral symptoms may restrict or inhibit these functional abilities, thereby negatively impacting QOL.[100] Symptoms such as sialorrhea (excess saliva production), xerostomia (dry mouth), and dysgeusia (altered sense of taste) are common oral symptoms and often occur together as part of a symptom cluster.[101]

Oral symptoms may be a direct result of physiologic changes to the oral mucosa known as *oral mucositis*. These changes are strongly associated with chemotherapy and radiation treatments and may include erythema, ulcerations, and soft tissue damage, as well as sensory disturbances in the mouth.[102] Long-term sequelae of mucositis include tissue fibrosis, salivary gland dysfunction, and increased susceptibility to mucosal infections, dental caries, and periodontal disease—all of which are risk factors for oral symptoms.[100,102] Beyond the oncology population, oral symptoms are common in end-stage cardiac, renal, and pulmonary disease, HIV/AIDS, and any other process affecting the salivary glands or saliva production.[100]

Pathophysiology of Saliva Production

The average amount of saliva generated by a healthy adult is between 800 and 1,500 milliliters daily,[103] which is produced primarily by three pairs of salivary glands in the oropharynx. The parotid, submandibular, and sublingual glands manufacture the majority of saliva; the remainder is released by thousands of minor glands in the epithelial lining of the mouth and the tongue. Parotid glands, located below and in front of each ear, produce watery, serous saliva.[103,104] Submandibular glands, located in the lower jaw, secrete mostly serous saliva with some mucinous elements.[103,104] Sublingual glands manufacture purely mucinous saliva.[103,104]

The salivary glands are activated by the parasympathetic nervous system. When gustatory nerves are stimulated, they release acetylcholine, which binds to muscarinic receptors on the salivary glands.[103] This facilitates an exchange of calcium, sodium, and chloride ions that pulls fluid from the cells and releases it through the salivary ducts via an osmotic gradient.[103] Within only a few seconds, the smell, sight, or taste of food triggers salivary production.

Saliva is 99% water. It also contains substances called mucins, which provide lubrication and protect the teeth and oral mucosa.[103,105] Mucins also aid in gustation and provide moisture for food-bolus formation. Saliva contains hundreds of solutes such as salts, proteins, minerals, enzymes such as ptyalin, antibodies, and other antimicrobial agents.[103] Solutes maintain a stable pH in the mouth, thus optimizing the sense of taste and inhibiting dental caries.[100] Antibodies and antimicrobial agents in saliva break down bacteria, viruses, and fungi, offering immunoprotection for the oral mucosa and dental structures.[103–105]

Oral Assessment and Examination

Any alterations in the normal process of saliva production may lead to oral symptoms. Thus, a complete oral assessment is fundamental to identification of oral symptoms. Thoroughly inspect the mouth and oral mucosa for signs of infection, gum disease, or dental caries. In particular, assess for ulcers or mucositis, as well as candidiasis. Examine the tongue for erythema or the presence of fissures, which may indicate a dry mouth. Salivary glands should be checked for swelling, a sign of obstruction. Oral appliances and dentures should be noted and their fit and condition assessed. Extraoral examination should observe for cracked lips, angular cheilitis (lip inflammation), or candida at the corners of the mouth. Note the presence of any oral symptoms such as dry mouth, altered taste sensations, or excess secretions.

If patients endorse the presence of oral symptoms, they may also report functional impairments with mastication, swallowing, and speech, as well as difficulties with dentures. Since oral complications frequently occur as part of a symptom cluster, assessment should include screening for related symptoms such as nausea, vomiting, oral pain, dysphagia, anorexia, weight loss, insomnia, and depression.[106,107] A thorough history should explore these problem areas, as well as evaluating subjective distress and reviewing current medications.[106,108] Finally, any recent sinus or upper respiratory infections, dental procedures, or ear, nose, and throat surgeries should be noted.

Nursing Interventions for Oral Symptoms

Oral health is often compromised in those who are seriously ill, and oral hygiene may be neglected. Illness-related changes in oral flora increase the risk of bacterial pneumonia as a result of aspiration of contaminated secretions.[109] Thus, a clean and moist oral cavity is not only important for patient comfort, but also may reduce infections and other complications. Mouth care, ideally with a toothbrush twice daily, is important for reducing oral debris.[110]

Other nursing interventions should include frequent oral assessments, suctioning of secretions as indicated, and providing moisture to the lips and oral mucosa.[111] It is important to carefully inspect and assess the condition of the entire oral cavity, using a flashlight if necessary. Extraneous secretions should be cleared regularly using mouth swabs, tongue scrapers, toothbrushes, and oral suction.

In hospitalized patients, humidification via a shovel mask or face tent may help to loosen secretions, moisten the oropharyngeal mucosa, and maximize comfort. Chlorhexidine, a broad-spectrum antibacterial agent, can be highly effective in reducing the risk of nosocomial respiratory infections and ventilator-associated pneumonia in critically ill patients[109,110] Oral care is particularly challenging to perform in patients with impaired cognition. Special considerations for the cognitively impaired patient include regular reminders and enlistment of family or care providers.[112]

Sialorrhea (Excess Oral Secretions) and Secretion Management

Definition

Sialorrhea, or excessive salivation and drooling, is typically due to the inability to control oral secretions and reduced swallowing function rather than a true salivary gland hyperfunction or hypersalivation.[113]

Impact

Sialorrhea can contribute to skin irritation, poor oral health, and dehydration and can increase the risk of aspiration pneumonia.[114] Furthermore, excessive drooling is embarrassing, isolating, and socially disabling.[114] Its presence can also impact mastication and speech intelligibility. In patients with impaired breathing and swallowing, the sense of choking and inability to clear saliva can be frightening and anxiety provoking.[114] Successful management of sialorrhea improves tolerance to noninvasive ventilation, a supportive treatment shown to increase life expectancy for patients with motor neuron disease.[113,114]

Incidence

Sialorrhea is common in patients with neurological conditions such as motor neuron disease/ALS, Parkinson's disease, and Alzheimer's dementia. It is estimated that up to 80% of patients with Parkinson's disease and 50% of patients with motor neuron disease experience sialorrhea, of which approximately 20% have moderate to severe symptoms.[113,115]

Etiology

Reduced frequency of swallowing, reduced oropharyngeal or laryngeal strength and/or sensation, inability to close the oral cavity, a weak cough with poor clearance of secretions,[114,115] and poor head posture are common causes of sialorrhea. Sensory dysfunction and/or lack of awareness of saliva build-up is also seen in some patients with neurologic disease, resulting in poor ability to recognize drooling.[116] Hypersecretion of saliva may also occur in the setting of oral or dental infection, as a side effect of medication (e.g., anticonvulsants, anticholinesterase, or lithium), or as a complication of gastroesophageal reflux.[116] Typically, when there is hypersalivation, the person is able to compensate by increased swallowing unless a concomitant dysphagia exists. Regardless of etiology, saliva pools in the mouth. In a patient with delayed or weak swallowing function or reduced oromotor strength, the pooled saliva either spills out anteriorly (e.g., drooling) and/or falls posteriorly into the pharynx and open airway, causing risk of choking and aspiration.

Assessment

Accurate assessment of the etiology, severity, and chronicity of sialorrhea is imperative to guide intervention decisions. Assessment should include gathering the history and timing of the secretions, understanding the burden of the secretion problem, reviewing other possible causes, and evaluating the type and frequency of secretions[115,116] (see Box 13.5). There are several objective rating scales in the literature that can be used to document the extent of sialorrhea, guide clinical decisions, and measure treatment effects (see Box 13.6).

Management

If evaluation reveals any reversible causes, these should be immediately addressed (e.g., treatment of oral infection, elimination of precipitating medications if possible, improved hydration, etc.). In the early stages, first-line management includes less invasive, nonpharmacological, behavioral, compensatory, and/or strengthening exercises via speech-language therapy, which may be helpful to improve oromotor function, sensation, and tongue control; self-management of saliva; triggers/reminders to swallow; and physical therapy and/or supportive neck collars for correction of body and head posture.[116,119]

Pharmacologic therapy is second-line therapy and aimed at saliva flow reduction. Anticholinergic medications block the parasympathetic stimulation to the salivary glands and thus reduce saliva production.[114,116,119] These medications include amitriptyline, benztropine, scopolamine patch, butylscopolamine, and sublingual atropine drops. Short-term use of glycopyrrolate bromide may be effective due to fewer anticholinergic side effects.

Anticholinergic side effects should be closely watched and monitored, including thickened/dried secretions which can be more difficult to expectorate, excessive dry mouth, urinary retention, drowsiness, confusion, and blurred vision, among others.[114,116,119] These side effects may be intolerable to the patient, leading to thickened secretions that are more likely to induce mucus plugging and resulting in poor oral hygiene.[119] Patients with sialorrhea who experience difficulty expectorating secretions may also find relief from a home/portable suction device and cough assist device.[116]

Botulinum toxin type A (BTx-A) and type B (BTx-B) are alternative options to treat sialorrhea in motor neuron disease and Parkinson's disease due to their reduced side-effect profiles. Botulinum toxin is injected subcutaneously under ultrasound guidance into the submandibular and parotid glands. Benefits are demonstrated at the first week after injection and last up to 3 months. The dosing should be controlled so that it does not induce excessive dry mouth and worsen dysphagia and difficulty chewing from diffusion of the toxin into nearby bulbar muscles.[113,114,116,119]

Radiation therapy to the parotid glands and submandibular glands is another alternative treatment for refractory sialorrhea or for those patients who cannot tolerate Botox injection or who still

Box 13.5 Guided Assessment of Sialorrhea

History: Timing during the day, chronicity, provocations

Medication review: Assess drug therapy for medications known to cause hypersalivation (neostigmine, clozapine, lithium, etc.)

Physical and oromotor exam: Sores on lips/chin, dental problems, health status of teeth, gums, oral mucosa, head posture, lip/tongue strength and sensation

Swallowing assessment

Imaging to rule out local abscess

Objective assessment of severity

Evaluation of type of secretions: Consistency, tenacious vs thin; frequency and quantification

Source: Adapted from References 113, 115.

Box 13.6 Sialorrhea (Secretion) Rating Scales

Oral Secretion Scale (OSS)

Targeted Population: Patients with amyotrophic lateral sclerosis (ALS) and Parkinson's disease (PD)

Measures: Saliva retention and swallowing

Scale design: Five grades of severity from very severe (0) to normal (4)

Sialorrhea Scoring Scale (SSS)

Targeted population: Patients with PD and children with developmental disabilities

Measures: Extent of drooling and location of wetness

Scale design: Nine grades of severity from least severe (1) to most severe (9)

Clinical Saliva Scale for Motor Neuron Disease (CSS-MND)

Targeted population: Patients with MND

Measures: Saliva burden and severity, effect of saliva on speech, use of NIV, social interactions

Scale design: Eight-item questionnaire, each rated from no problem (0) to severe problems (3)

Source: References 117, 118.

have not achieved adequate reduction.[113,114,116] Treatment duration is up to 9 months, often necessitating repeat therapy. Access to radiation treatment is limited by location, procedure, and cost.[114] Radiotoxicity can occur resulting in excessive dry mouth, facial pain and erythema, dental caries, and nausea.[119]

Last, surgical resection of either the parasympathetic neural pathway or of the submandibular and salivary glands or submandibular duct rerouting for severe cases can be performed.[114,116,119] Although effective, surgical intervention is invasive and the benefits and burdens of treatment must be considered.

Xerostomia (Dry Mouth)

Definition

Xerostomia is the sensation of oral dryness, which may or may not be accompanied by a decrease in salivary secretions (hyposalivation). True xerostomia results from dysfunction of the salivary glands themselves.[120] However, even with normal salivary gland function and saliva production, many patients report oral dryness, known as "symptomatic" or "pseudo" xerostomia.[120] It is often difficult to identify the exact underlying cause and/or contributing factors for this bothersome symptom.[103,120]

Impact

Decreased saliva and prolonged xerostomia cause significant symptoms in the oral cavity, including dental caries; oral pain and burning; lesions of the tongue, lips, gums, and oral mucosa; mouth infections such as candidiasis; taste changes; and bad breath.[103,112,120,121] In the esophageal region, problems include swallowing difficulties, along with alterations in speech formation and voice function.[103,112,121] Eating may be impaired due to chapped lips, difficulty chewing, and the need for frequent sips of liquid to mobilize food.[112,120,121]

Xerostomia negatively impacts QOL and may cause physical discomfort as well as emotional suffering and a retreat from socializing.[122] Social rituals, particularly meals, are a time to communicate, laugh, smile, and eat. Unfortunately, poorly controlled xerostomia may prevent patients from performing these functional activities. Adequate treatment offers not only increased comfort, improved nutrition, and better dental health, but also the benefit of a social structure that promotes effective coping.[122]

Incidence

Studies suggest that between 5.5% and 46% of patients experience xerostomia.[123] In palliative care, dry mouth may affect as many as 30% of patients.[124] Although well-described in the literature as a cancer-related symptom, xerostomia is also common in the later stages of diabetes, renal failure, cardiac disease, and liver disease, as well as in autoimmune diseases such as AIDS and Sjögren's syndrome.[120,121] The risk of xerostomia escalates with age and number of medical problems, in part because the symptom can be triggered by a wide array of medications.[123]

Etiology

The cause of xerostomia is reduced salivary secretions, which may result from infection, dehydration, endocrine and autoimmune processes, or age-related changes.[120,121] Medications are also notorious culprits of dry mouth, particularly those routinely used in palliative care, including sedatives, tranquilizers, antihistamines, antiparkinsonian medications, antiseizure medications, skeletal muscle relaxants, tricyclic antidepressants, and anticholinergics.[103,120,121,123] In general, the number of comorbidities with resultant complex pharmacotherapy increases the risk of xerostomia.[103,120]

Buccal erosion is another common cause of xerostomia. It frequently occurs as a result of cancer-directed therapies, particularly radiation treatment for head and neck cancers.[103,120,125] Although dose and duration of radiation exposure affect the degree of xerostomia,[126] reversible dysfunction of salivary glands may begin with doses as low as 10 Gy.[120] Irreversible gland degeneration and resulting decrease in saliva production typically occur at doses of 60 Gy or greater.[103] In up to 60% of patients, xerostomia develops within the first few days of irradiation.[127] In addition, many chemotherapeutic and cytotoxic agents used to treat malignancies produce mucosal alterations that may result in a dry mouth.[125]

Xerostomia may contribute to or exacerbate existing mental health issues such as depression and anxiety, thus leading to greater symptom burden and impaired coping.[120,122] Due to diurnal saliva production, xerostomia may worsen at night, resulting in sleep interruptions or insomnia. Finally, dry mouth may render the management of plaque and gums difficult, particularly in older adults or those with significant fatigue.[125,128] Patients undergoing cancer treatment or other immunosuppressive therapies may be unable to tolerate dental procedures.[125] Thus, patients may experience discomfort not only from their underlying illness but also from subsequent oral complications.

Assessment

Assessment should include patient rating in eight aspects of xerostomia, including overall mouth and lip dryness, speech, chewing, sleeping, dry mouth with eating and swallowing, resting, and the frequency of sipping liquids for eating and during the rest of the day.[106,107] Sample questions appear in Box 13.7.

Box 13.7 Xerostomia Assessment Questions

Do you experience dry mouth? How frequently?
Does dry mouth bother you?
Do you have dry lips?
Do you have dry nasal passages?
Do your gums bleed when you brush your teeth?
Is your tongue red and raw?

Do you find there are times you need to drink more fluids? When?
Do you experience difficulty speaking due to a dry or sticky mouth?
Do you have difficulty chewing? What types of foods?
Do you have difficulty swallowing? Solids or liquids?

Do you need extra fluid to help you swallow food? All foods or solids or semi-solids?
Do you use hard candies or gum for your dry mouth?
Do you find your sleep is disrupted by a dry mouth? How often do you wake up at night because of a dry mouth?
Have you experienced altered taste sensations? What types of tastes? Any types of foods?

Do you use tobacco? How often?
Do you drink alcohol? How often?
Do you drink caffeine? In what drinks? In what foods?
Are you taking any prescription medications, over the counter medications or preparations?

Source: References 106–108.

Diagnostic tests for xerostomia incorporate dry mouth evaluation and saliva measurement. One standard bedside evaluation is conducted by giving the patient a dry cracker or biscuit. Xerostomia is present if the patient cannot eat the cracker without taking extra fluids.[129] An alternate test is performed at the conclusion of mouth inspection by placing a tongue blade or dental mouth mirror directly on the tongue. Since dry mouth creates a ropey, pasty saliva, the object will stick to the tongue of a patient with xerostomia.[120,121] Another more precise option is sialometry, or the actual measurement of saliva flow through collection in a container or on a cotton swab.[120,121] However, for most palliative care patients, this is burdensome and unnecessary.

Documentation of the extent of xerostomia is essential. There are many rating scales specifically designed for this purpose. Several rating scales described in Box 13.8 are based on the appearance of oral mucosa.

Management

Much of xerostomia management focuses on interventions to alleviate rather than to eradicate or to prevent the symptom. A stepwise approach should guide management and treatment, as described in Box 13.9. Pharmacological interventions are outlined in Table 13.6.

Nonpharmacological interventions (see Table 13.7) should be tried first, as they may be less expensive and pose a lower side effect profile. Acupuncture is one promising nonpharmacologic approach for the prevention and relief of dry mouth, particularly among patients receiving radiation therapy. A recent randomized controlled trial for patients with radiation-induced xerostomia revealed fewer reports of dry mouth after 8 weeks of acupuncture treatments when compared to standard oral therapies.[133] In an earlier study utilizing acupuncture concurrently with radiation, patients with nasopharyngeal cancer reported decreased incidence and severity of xerostomia and improved QOL.[134]

Box 13.8 Dry Mouth Rating Scales

American Dental Hygienists Association

Tissue changes (tongue and mucosal color)
Oral disease (bad breath, cavities, infection)
Saliva, glands and function

American Cancer Society Radiation Side Effects-Dry Mouth

Decreased saliva
Thick saliva
No saliva

Oncology Nursing Society Xerostomia

0 No dry mouth
1 Mild dryness, slightly thickened saliva; little change in taste
2 Moderate dryness, thick and sticky saliva, markedly altered taste
3 Complete dryness of mouth
4 Salivary necrosis

Source: References 106, 130, 131.

Box 13.9 Stepwise Process for Managing Xerostomia

1. Treat underlying oral infections.
2. Review current medications, eliminating any that promote dry mouth. If elimination is not possible, consider decreasing the dose or modifying the schedule so that the peak effect does not coincide with diurnal decrease in salivary production.[123]
3. Stimulate salivary flow using either nonpharmacological or pharmacological interventions.
4. Replace lost secretions with spray saliva substitutes.
5. Protect teeth. Continue meticulous mouth care. Promote use of fluoride rinses.
6. Rehydrate. Encourage plenty of liquids.
7. Modify diet to avoid mouth pain from acids or hard foods.

Source: References 108, 132.

Dysgeusia

Definition and Impact

Dysgeusia is an alteration or distortion in the perception of taste, usually described as being unpleasant. Patients with dysgeusia may report taste sensations that are abnormally bitter, salty, or metallic.[136] Dysgeusia may be experienced along with decreased sensitivity to taste (known as hypogeusia) or even absence of the sense of taste (known as ageusia).[137] Taste alterations may result in poor appetite, food aversions, decreased oral intake, and subsequent weight loss and malnutrition.[136–139] Furthermore, the associated inability to enjoy food and the social aspect of mealtimes may negatively impact overall QOL for patients with dysgeusia.[135,137,138]

Incidence

Dysgeusia occurs frequently among cancer patients who are undergoing chemotherapy and/or radiation treatments; as a result, much of the literature focuses on these populations. In one systematic review, dysgeusia was endorsed by 56.3% of cancer patients receiving chemotherapy only, 66.5% of patients receiving radiation therapy only, and 76% of patients treated with both chemotherapy and radiation.[139] Patients with head and neck cancer are among those most at risk for dysgeusia.[137]

Etiology

Among cancer patients, taste alterations may be the result of specific treatment modalities. While the precise mechanism of dysgeusia is not fully understood, it is generally accepted that damage to sensory receptor cells is the underlying cause of the symptom. The turnover rate of taste bud receptor cells is only about 10 days, rendering them particularly susceptible to chemotherapeutic agents and radiation, both of which destroy large numbers of cells with high turnover rates.[136,139] In addition, radiation may alter the anatomical structure of taste buds, thus reducing the ability of receptor cells to interact with the flavor molecules in food.[139] Finally, exposure to chemotherapy may cause alterations in neuronal cells as well, thus producing specific taste sensations even without the presence of receptor cell stimulation by flavor molecules.[139]

Table 13.6 Pharmacological interventions

Medication	Description	Dose	Drug Information
Pilocarpine	Nonselective muscarinic agonist and parasympathetic agent. Increases exocrine gland secretion and stimulates tissue in damaged salivary glands. Increases saliva production. Recent studies have shown that pilocarpine given before and during radiotherapy can reduce xerostomia.	5 mg tid	Response varies and depends on presence of functional salivary gland tissue. Optimal effect may require 2–3 months of use. Use cautiously in patients on beta-blockers, with cardiovascular or pulmonary disease, gastric ulcers, or glaucoma. Side effects include vision changes, sweating, nausea, diarrhea, urinary frequency, rhinitis, bradycardia, and bronchoconstriction.
Bethanechol	M3 muscarinic agonist. Resistant to cholinesterase. Also used to relieve anticholinergic side effects of tricyclic antidepressants.	25 mg tid	Side effects include nausea and diarrhea.
Yohimbine	Blocks alpha-2 adrenoreceptors.	14 mg/day	Side effects include drowsiness and confusion.
Cevimeline	Muscarinic agonist. Stimulates M1 and M3 receptors in lacrimal and salivary glands. Acts to increase saliva by inhibiting acetylcholinesterase.	30 mg tid	Less effective than pilocarpine. Use cautiously in patients on beta-blockers, with cardiovascular or pulmonary disease, or gastric ulcers. May cause dyspepsia. Overall fewer side effects compared to pilocarpine as it does not act on M_2 receptors. Less risk of bradycardia.
Antifungals	Used to treat xerostomia resulting from oral candidal infections.		First-line treatment is nystatin (suspension or troches, depending on swallowing ability), which may be expensive. Second-line treatment includes fluconazole, first dose 200 mg PO/IV. Fungal infections of the lips may require miconazole, clotrimazole, or ketoconazole.

Source: References 108, 120–124.

Table 13.7 Nonpharmacological interventions for xerostomia management

Intervention	Role/Effect	Comment
Preventative Measures		
Oral care	Reduces xerostomia severity. Promotes well-being.	Frequent soft brushing, water jet, denture cleaning, fluoride rinses, mouthwash, and flossing can stimulate salivation. Can help prevent candidiasis, since dentures can harbor infections.
Lip protectants	Prevents cracked lips and moistens skin. Includes use of lip barriers such as balms or ointments.	Avoid products containing alcohol, since these can be irritating. For angular cheilitis at the corners of the mouth, protect with lanolin and KY Jelly.
Dentifrices	Uses a paste or powder to clean teeth.	Several products contain antimicrobial enzymes to reduce oral infections and enhance mouth wetting. Examples are Biotene, Oral Balance, and Oasis.
Mouthwashes (non–alcohol containing)	Helps rinse debris from mouth.	Includes homemade mouthwashes made from saline, sodium bicarbonate, glycerin.
Diet modifications		
	Allows patient to eat.	Suggest soft-textured foods, as they are better tolerated (soup, pudding, mashed potatoes, and shakes). Instruct patient to take fluids with all meals. Add gravies and juices to food to aid swallowing. Apply olive oil to the gums and mucosa to act as a lubricant while eating. Educate patient regarding the avoidance of sugars and spicy foods. Carbonated drinks (ginger ale) or citrus juices (lemonade, pineapple, papaya) may be refreshing; however, citrus may be too irritating for patients with oral ulcerations.
Nonpharmacological		
Peppermint water	For mucous saliva.	Inexpensive.
Vitamin C	Disrupts salivary mucin and reduces viscosity of saliva.	Use in lozenges or other forms as preferred. May be irritating to the mouth, particularly if the patient has mouth sores. Can erode dental enamel.

(*continued*)

Table 13.7 Continued

Intervention	Role/Effect	Comment
Citric acid/sweets	For mucous saliva.	May cause burning sensation in mouth In sweets, can cause dental caries.
Chewing gum, mints	For watery saliva. Acts on chemoreceptors and mechanical receptors to stimulate saliva. May create a buffer system to compensate for dietary acids.	Chewing gum is more effective than mints. Recommend sugar-free gum/mints to prevent dental caries. Consider the social acceptance of gum chewing, particularly in older populations. Side effect of diarrhea from sorbitol if too much gum or mints ingested.
Rehydration	Replenishes lost moisture.	Encourage oral hydration by sipping water and other fluids. Includes adding humidity to oxygen systems or using vaporizers to combat the drying effects of indoor heating and air conditioning. Instituting these measures at night may promote sleep.
Saliva Replacement		
Water sprays or sip	Reduces oral pain and increases saliva.	Short-acting. Accessible. Use warm versus cold water based on patient preference.
Artificial saliva	Provides saliva substitute to lubricate oral mucosa.	Comes in gel or spray formula. Dose 2 mL every 3–4 hours. Contains carboxy-methylcellulose or mucin, which are animal products. Consider patient's religious beliefs and dietary preferences when recommending. Products with a mucin base may be better tolerated than those derived from carboxy-methylcellulose.
Procedures		
Laser treatment	Stimulates saliva production.	Longer lasting, expensive. Administered to salivary glands in an office setting.
Electrostimulation	Stimulates saliva production.	Longer lasting, less expensive than laser treatment. Delivered to the glands and tongue via a battery-operated process.
Acupuncture	Increases saliva production.	Weekly or regular intervals. Variable cost, can be expensive.

Source: References 105, 108, 112, 128, 135 (http://www.nidcr.nih.gov).

Taste disturbances are a common side effect in neurologic diseases such as Parkinson's disease, ALS, multiple sclerosis, and Alzheimer's dementia.[136] Other serious illnesses associated with dysgeusia include diabetes, hypothyroidism, and liver disease. More benign factors such as poor dental hygiene, periodontal disease, mucosal infection, tobacco use, and diet are also frequent contributors and should be considered in patients with serious illness.[136,139] Upper respiratory disease and sinus infections may interfere with olfaction and produce foul-tasting mucous that alters taste sensations.[136]

Medications also cause dysgeusia. Chemotherapeutic agents may produce a bitter or metallic taste in the mouth, which occurs when compounds in the drugs enter the oral mucosa.[136] Certain chemotherapy-containing antimetabolites combined with platinum derivatives (used for colon cancer) or with cytotoxic antibiotics, anthracyclines, or vinca alkaloids (used for lymphomas) are more likely to induce dysgeusia.[138] Taxane-based chemotherapy used in the treatment of breast cancer is also associated with increased risk of dysgeusia.[138,140] Other medications associated with dysgeusia are outlined in Table 13.8.

Table 13.8 Medications associated with dysgeusia

Category	Medications
Antibiotics	Ampicillin, macrolides, quinolones, sulfamethoxazole, trimethoprim, tetracycline, metronidazole
Neurologic medications	Migraine medications, anti-parkinsonian medications, muscle relaxants
Cardiac medications	Antihypertensives, antiarrhythmics, statins, diuretics
Psychotropics	Tricyclic antidepressants (TCAs), antipsychotics, anxiolytics, mood stabilizers
Other	Antihistamines, bronchodilators

Source: References 141, 142.

Assessment

Patient self-report is considered the gold standard in assessing taste disturbances. Clinical tests to evaluate taste function do exist and utilize various techniques to apply concentrated flavor solutions to the mouth and tongue in order to test thresholds for taste identification.[136,137,143] However, these tests are complex, costly, and not generally useful in the palliative care population.

Management

Pharmacological Interventions

Research exploring pharmacologic interventions for dysgeusia is limited. Zinc supplementation as a potential treatment for taste disturbances has been studied. Among patients with head and neck cancer, the value of zinc supplementation was inconclusive, with two studies supporting its role and two demonstrating no benefit.[143] In noncancer patients, a recent meta-analysis evaluating zinc supplementation found only low- to moderate-quality evidence to improve taste perception or health-related QOL, with the best results occurring among patients who had known zinc deficiencies.[144]

A variety of other medications for managing dysgeusia appear in the literature, yet they also lack the support of robust research. In a small trial for patients with idiopathic dysgeusia, alpha lipoic acid produced complete resolution of the symptom in 46% of patients and mild to moderate improvement in up to 91% of patients as compared to a control group.[140] In another isolated study of low-dose dronabinol administration, 55% of participants reported that the drug "made food taste better" compared to 10% of the placebo group.[145] Finally, a trial of the fruit *Synsepalum dulcificum* (miracle fruit) tested the food's ability to mask unpleasant flavors in patients with dysgeusia. Participants who consumed the fruit prior to meals reported positive taste changes and increased food intake.[143] Additional pharmacologic interventions for dysgeusia with little or no supporting evidence include amifostine, glutamine, and gingko biloba.[143,144]

Nonpharmacological Interventions

Little evidence supports nonpharmacological interventions for dysgeusia. One qualitative study of breast cancer patients who experienced dysgeusia while receiving taxane-based chemotherapy identified a range of strategies, including trying recipes that differed from their usual choices, eating strongly flavored foods, honoring specific food cravings, eating sugar-free candy before meals, cutting food with lemon, drinking sweetened beverages, using plastic cutlery, drinking from a straw, brushing one's teeth and tongue before meals, and using baking soda and salt wash or antibacterial mouthwash.[146] In another study of patients undergoing chemotherapy, an educational initiative provided a checklist of suggested dietary modifications. Among the most helpful interventions were avoidance of strong-smelling or strong-tasting foods, consumption of bland foods, drinking more water with foods, oral care prior to eating, and eating smaller, more frequent meals.[147] While dietary interventions may provide some benefit, more research is necessary to determine the most effective interventions.

Conclusion

Dysphagia, hiccups, and other oral symptoms commonly occur in advanced disease processes and can cause significant burden for both the patient and the caregiver. Swallowing difficulties may not only impede adequate nutrition and hydration but also impact QOL and social interactions. Symptoms such as hiccups, sialorrhea, xerostomia, and dysgeusia may seem inconsequential and are often overlooked by clinicians. However, these conditions are a visible aspect of a person's well-being. Whether experienced individually or as a symptom cluster, oral symptoms often considerably impact QOL for palliative care patients.

Management of dysphagia, hiccups, and oral symptoms in patients with serious illness focuses on preventing functional decline, maximizing comfort and QOL, and supporting the patient's wishes. Working with an interdisciplinary team to find solutions will offer optimal relief to patients and their families. Nurses may be the first to identify the presence of these symptoms and to understand their negative impact on QOL. Oral care is an essential intervention for dysphagia, sialorrhea, xerostomia, and dysgeusia. Nurses should address continued oral care as a vital aspect of promoting dignity, comfort, and QOL for patients with troublesome oral symptoms.

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CHAPTER 14

Bowel Management

Constipation, Obstruction, Diarrhea, and Ascites

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Key Points

- Constipation and diarrhea are common symptoms in the palliative care population and should be monitored closely with treatment based on cause.
- Malignant bowel obstruction and ascites can severely impact patient quality of life and require diligent assessment and active management.
- Palliative care involves providing patients with realistic expectations in addition to attentive management of symptoms affecting quality of life.

Constipation

Case Study 1: A Patient with Lung Cancer

Mr. B is a 78-year-old man with advanced non–small cell lung cancer, currently receiving paclitaxel and cisplatin therapy. Recently, his pain increased, and his opioid regimen was escalated accordingly. During his clinic visit, he mentions that he has not had a bowel movement in 5 days and feels uncomfortable. He has tried increasing fluids and taking over-the-counter stool softeners without relief.

Prevalence and Impact

Fourteen percent of the general population suffers from constipation, and 30–100% of patients with palliative needs are affected.[1,2] This broad range is primarily due to lack of consensus on the definition of constipation. In one study of a palliative population by Erichsen et al., 7% of patients had medical constipation (defined as fewer than three bowel movements per week), 19% had “perceived” constipation, and 15% had both medical and perceived constipation. Of those with constipation, 71% reported severe symptoms.[3]

Given the high prevalence, it is not surprising that constipation results in increased healthcare utilization. More importantly, constipation is associated with impairment of physical activity and decreased work productivity and may also contribute to symptoms of anxiety and depression, all of which lower health-related quality of life (QOL).[4–6] Up to a third of patients taking opioids for pain will decrease or discontinue their opioids due to opioid-induced constipation, choosing inadequate pain relief over this common side effect.[5,7] Additionally, patients may develop “catastrophic” thinking, wherein they associate constipation with rapidly declining health.[5]

Definitions

There is no widely agreed upon definition for constipation, and it is often interpreted subjectively. Common descriptions include decreased frequency of bowel movements, hard and/or small stools, straining or difficulty with evacuation of stool, and a sensation of bloating or fullness. The Rome I criteria were established in 1994 to more objectively define clinical constipation, and in 2016, the revised Rome IV criteria were published (see Box 14.1).[8–11]

Clark et al. suggest that, in defining constipation, four domains are considered: (1) any long-standing history of bowel dysfunction as determined using the Rome criteria, (2) evaluation of physical dysfunction that may contribute to normal defecation, (3) the patient’s subjective report of constipation based on straining and feelings of bloating or incomplete evacuation, and (4) objective measures such as stool frequency and consistency.[12]

Pathophysiology and Risk Factors

The normal gastrointestinal (GI) physiology is complicated and involves a combination of fluid regulation and intrinsic and extrinsic neurologic factors. Transit time is between 2 and 5 hours in the small intestine,[13] and 10–59 hours in the large intestine,[14] but these times can be altered by anything that affects the fluid balance or motility of the gut.

The causes of constipation can be broken down into primary and secondary causes. Primary causes include reduced fluid and fiber intake,[15] as well as decreased activity and mobility. Additional risk factors for constipation are female sex, increased age, and a lack of privacy or routine, as occurs with a hospitalized patient.[1,16] Requiring a bedpan or commode can be physically uncomfortable, adding to the challenge of defecation.

Box 14.1 Rome IV Criteria for Diagnosis of Clinical Constipation

Two or more of the following are present over the past 3 months, with initial onset at least 6 months prior:

- Straining more than 25% of the time.
- Lumpy/hard stool more than 25% of the time.
- Sensation of incomplete evacuation more than 25% of the time.
- Sensation of anorectal obstruction/blockage more than 25% of the time.
- Manual maneuvers (e.g., digital disimpaction) needed to stimulate more than 25% of bowel movements.
- Fewer than three spontaneous bowel movements per week.

Additionally, loose stools rarely occur without use of laxatives, and the patient meets insufficient criteria for irritable bowel syndrome.

Secondary causes of constipation are numerous and include structural, metabolic, neurologic, psychologic, and iatrogenic factors.

Structural Factors

Structurally, anything that impedes passage within the gut can contribute to constipation. This includes primary tumors of the pelvis or abdomen (e.g., cancer of the colon, pancreas, uterus, ovaries, and cervix) or metastases, as well as partial bowel obstruction from malignant or other causes. Patients with prior abdominal or pelvic surgeries may have surgical interruption of the GI tract or postsurgical adhesions that slow gut motility.[16] Abdominal muscle weakness also contributes to constipation by making it difficult to develop the necessary intraabdominal pressure required to have a bowel movement. Similarly, pelvic floor dysfunction can cause difficulty coordinating the act of defecation. External hemorrhoids and anal fissures result in discomfort during defecation and may discourage the patient from having bowel movements in a timely manner, further leading to irregular stooling.[17]

Metabolic Factors

Electrolyte abnormalities affect gut motility, thus contributing to constipation. Hypercalcemia, which is common in patients with multiple myeloma, other malignancies, or hyperparathyroidism, is often associated with constipation, as are hyponatremia and hypokalemia. Prolonged hyperglycemia can result in diabetic autonomic neuropathy, which increases the transit time of the gut. Hypothyroidism and the uremia associated with renal failure are other metabolic risk factors for constipation.

Neurologic Factors

Any neurologic condition that affects the autonomic, somatic, or enteric nervous systems may lead to constipation. Injury or compression of the lumbosacral spinal cord, cauda equina syndrome, paraplegia, and stroke with resultant paresis all affect a patient's ability to coordinate bowel movements. Patients with Parkinson's disease have a high risk for constipation. Other neurologic conditions, such as cerebral tumors and paraneoplastic autonomic neuropathy, are also associated with constipation.[16]

Psychologic Factors

Psychologic and psychosomatic factors also play a role in constipation, including depression. Painful past experiences or cultural beliefs relating to privacy may affect someone's comfort level in successfully having a bowel movement.[5]

Iatrogenic Factors

Some of the most common causes of constipation are iatrogenic in nature, resulting from medications. Opioids in particular contribute significantly to constipation in the palliative population. Up to 47% of patients taking opioid medications in general and 72% of those specifically taking oral morphine suffer from opioid-induced constipation (OIC). Higher doses and longer duration of use further increase the risk.[5,18] The analgesic effect of opioids occurs through binding of mu receptors within the central nervous system. OIC, on the other hand, occurs when these agents bind to opioid receptors within the myenteric plexus of the GI tract, resulting in decreased bowel transit times, increased fluid reabsorption, decreased GI chloride secretion, and stimulation and decreased relaxation of the pyloric and internal anal sphincters.[18,19] Unfortunately, while most opioid side effects improve over time, tolerance does not occur with constipation.[20]

Other medications that commonly contribute to constipation are listed in Box 14.2.

Box 14.2 Medications Commonly Associated with Constipation

- *Chemotherapy*: Any agent that results in autonomic nervous system dysfunction[16,21]
  - Vinca alkaloids
  - Taxanes
  - Oxaliplatin
  - Temozolomide
  - Thalidomide
  - Bortezomib
- *Anticholinergic medications*: decrease GI motility and fluid secretion[16]
  - Antihistamines
  - Antidepressants (tricyclic antidepressants in particular)
  - Antispasmodics (e.g., dicyclomine)
  - Anti-parkinsonian medications
- Diuretics: May cause dehydration, leading to increased risk of constipation (e.g., furosemide)
- Anticonvulsants (e.g., gabapentin, pregabalin, phenytoin)
- Neuroleptics (e.g., haloperidol, chlorpromazine)
- Supplements (e.g., calcium, iron)
- 5-HT3 antagonist antiemetics (e.g., ondansetron)
- Muscle relaxants (e.g., cyclobenzaprine)
- Calcium channel blockers (e.g., amlodipine)

Source: References 18, 19.

Assessment

History

A good evaluation always starts with review of past medical and surgical history, medication use, and an assessment for any of the risk factors discussed in the pathophysiology section. Because there is a range of normal bowel function, the patient's previous bowel habits should be ascertained and symptoms discussed in regards to deviation from baseline. Although noting a recent change in fluid and oral intake is helpful information, it is important to note that bowel movements are still expected even in the absence of good oral intake, since not only food, but also sloughed cells of the GI tract and bacteria contribute to stool content.

Patients with constipation may report bloating, early satiety, abdominal pain, nausea, vomiting, and malaise. However, some studies suggest a patient's self-report of "yes" or "no" when asked if they have constipation may not be useful for clinical practice given the low correlation of their response with clinical criteria. Rhondali et al. suggest that, in the advanced cancer population, a simple scale from 0 to 10 may be more helpful than an answer of "yes" or "no." A positive screen constitutes a score equal to or greater than 3 as this resulted in 84% sensitivity and 62% specificity.[22] It is additionally important to assess for "red flags" that could indicate a serious issue, such as bloody or melenic stools, severe and intractable nausea or abdominal pain, significant weight loss, concurrent anemia, or family history of GI malignancy.[20]

Many scales have been proposed to better understand a patient's symptoms. The Constipation Assessment Scale and the Bowel Function Index are two commonly used screens that are reliable and validated, and these are discussed further in Table 14.1.[21]

Physical Examination

A thorough abdominal exam is an important component of evaluating constipation and should include visual inspection for surgical scars, distension, or skin changes. Auscultation can provide information on whether the bowels are moving, and percussion may be dull over colon filled with stool versus tympanic over areas filled with gas. A clinician should palpate for masses or ascites to assess for risk factors for constipation and may at times actually be able to palpate a fecal mass in the descending colon, with an associated "crepitus" sensation due to entrapped gas.[17]

A rectal exam should be performed (except in cases of thrombocytopenia or neutropenia, which increase the risk of bleeding and infection, respectively). This can exclude fecal impaction or diagnose external hemorrhoids, fissures, or ulcerations, all of which can be associated with constipation. In some cases, evidence of rectal prolapse or masses may be evident and require further evaluation.[17] Presence of bloody stool may be suggestive of hemorrhoids, colitis, or tumor.

A neurologic examination may assist in ruling out central nervous system or spinal cord abnormalities that could predispose a patient to constipation.[1]

Diagnostic Studies

While imaging studies are not generally indicated in the evaluation of constipation,[23] a plain abdominal radiograph or computed tomography (CT) scan may be considered in high-risk patients to exclude bowel obstruction.

When clinically indicated, calcium, sodium, potassium, and glucose levels may assist in assessment of metabolic risk factors, and a complete blood count can be helpful in excluding associated anemia, thrombocytopenia, and neutropenia.[1] Thyroid-stimulating hormone may also be considered if there is suspicion for hypothyroidism contributing to constipation.

Management

Nursing Interventions and Supportive Care

Patient education is a key component of constipation management and includes an awareness of risk factors as well as advice on how oral intake and behavior affect symptoms. Patients should

Table 14.1 Scales to assess constipation

Constipation Assessment Scale [21]	Bowel Function Index[18]
Self-administered	Clinician-administered
Relates to last 7 days	Relates to last 7 days
Rate presence and severity of symptoms: 0 = " no problem" 1 = "some problem" 2 = "severe problem"	Rate following items:
◆ Abdominal distension or bloating ◆ Change in amount of gas passed rectally ◆ Less frequent bowel movements ◆ Oozing liquid stool ◆ Rectal fullness or pressure ◆ Rectal pain with bowel movement ◆ Small volume of stool ◆ Unable to pass stool	◆ Ease of defecation (0 = easy/no difficulty; 100 = severe difficulty) ◆ Feeling of incomplete evacuation (0 = not at all; 100 = very strong) ◆ Patient's judgment of constipation (0 = not at all; 100 = very strong)
Total score of 0 = "no constipation" Total score of 16 = "severe constipation"	Patients already on first line interventions scoring 30 or more should be considered for prescription medications.
	Commonly used in OIC studies for patients already on prophylactic or first line interventions. Recommended by the American Academy of Pain Medicine.

Box 14.3 Suggested Algorithm for Management of Constipation

Stage 1

- Provide education on increasing fluids, dietary fiber, and exercise, if able.
- Assess for risk factors, including new constipating medications.
- Patients on opioids should be started on prophylactic bowel regimen unless otherwise contraindicated: stimulant laxative:
  - Sennosides 8.6 mg, 2 tablets at bedtime

Stage 2

- Titrate sennosides up to 4 tablets twice a day as needed, and/or:
- Add one of the following
  - Polyethylene glycol 17 g in an 8-ounce beverage once a day
  - Milk of magnesia 10 mL orally 2–4 times per day (limit use in patients at risk of electrolyte abnormality or renal dysfunction)

Stage 3

- Perform digital rectal exam to rule out impaction (excluding patients with neutropenia, thrombocytopenia)
  - If impacted and soft, manually disimpact
  - If impacted and hard, consider mineral oil or milk and molasses enema
  - Consider short-acting analgesic and/or anxiolytic prior to disimpaction
- If not impacted, consider use of lactulose 15–30 mL orally 3–4 times a day or bisacodyl suppository daily as needed
- Consider abdominal imaging if concern for obstruction or high impaction
- Consider bowel management consult

Source: Adapted in part from References 16, 39.

be given a goal, such as aiming for one unforced bowel movement per day (Box 14.3).

Even though many palliative patients have poor oral intake, they should be informed to still expect some stool output, even if it is less than usual. There is limited evidence that increasing oral fluids helps with constipation except for those with dehydration[4]; however, many clinicians recommend a daily goal of eight 8-ounce glasses of fluid unless otherwise contraindicated. From a nutritional viewpoint, increasing dietary fiber to 20–35 g/day (including high-fiber foods like prunes, apples, and pitted fruits, as well as green, leafy vegetables, whole grains, and bran) is recommended,[4,16] except for those at high risk of bowel obstruction. Other dietary recommendations include avoidance of constipating foods, like dairy products (e.g., cheese, ice cream), red meat, and processed foods.

There is limited evidence that exercise helps constipation, and exercise may be technically challenging for the palliative population to perform; however, expert opinion suggests activity be increased if the patient is able.[4] Allowing for privacy, easy access to facilities or commode, and routine (colonic motility is highest in the morning) are straightforward interventions that can help prevent and improve constipation.[4] There is some evidence that clockwise abdominal massage increases intraabdominal pressure with resultant improved bowel function[5] and can be easily performed by nursing staff or a family member. Using a footstool, squatting, or leaning forward during defecation relaxes the puborectalis muscle, allowing for easier passage of stool.[24]

When indicated, manual fecal disimpaction is a nursing intervention that can provide significant relief to the constipated patient. Appropriate analgesia and/or anxiolytics should be considered beforehand. Disimpaction should be avoided in patients with thrombocytopenia or neutropenia.

Pharmacologic Management

An initial pharmacologic approach includes avoidance of constipating medications when possible (e.g., considering an antiemetic other than ondansetron). Increasing the use of nonsteroidal anti-inflammatory drugs (NSAIDs), acetaminophen, and adjunctive pain medications may decrease a patient's risk of OIC by decreasing opioid requirements.[25] Oral morphine has been shown to result in higher laxative utilization and increased constipation compared to transdermal fentanyl, so opioid selection may also be relevant.[26] In patients taking opioids, a prophylactic bowel regimen is recommended unless otherwise contraindicated,[17,25] and as opioid doses increase, the bowel regimen should be adjusted accordingly.

Oral laxatives are generally utilized as first-line pharmacologic treatment of constipation.[17] However, there are minimal data on the safety and efficacy of laxatives in the palliative population.[17] A 2015 Cochrane review of palliative patients with constipation suggested similar efficacy between multiple laxatives; however, many common laxatives were not included, and the overall quality and amount of included studies was low.[27] Though there is not a specific, widely agreed upon protocol for laxative use, the European Consensus Group on Constipation in Palliative Care recommends a combination of osmotic and stimulant laxatives in the palliative population,[17] and many clinicians will take a similar approach. There are many types of laxatives available, which are discussed in more detail below.

Bulk Laxatives

Bulk laxatives are indicated for patients with mild constipation and irritable bowel syndrome. These are typically not effective as sole agents in patients with OIC[16] and should be avoided in those with significantly reduced physical activity and poor fluid intake due to increased risk of bowel obstruction, which limits the utility in the palliative population.[5] The mechanism of action includes increased GI fluid retention, leading to larger and softer stools.[5] Common adverse effects include abdominal distension and flatulence; less commonly, fluid retention and hyperglycemia may occur. Onset of action is typically 12–24 hours, though this may be 72 hours or more.[5] Bulk laxatives should be taken with two 8-ounce glasses of water. Some examples of bulk laxatives include:

- Psyllium 4–6 g/day
- Methylcellulose 4–6 g/day
- Barley malt extract before meals and at bedtime

Surfactant (Detergent, Emollient, Softener) Laxatives

Surfactant laxatives are most effective when stools are hard, and these can be considered in patients who should not be straining (e.g., recent surgery, hypertension). In many cases, a surfactant is not sufficient as monotherapy, and while some use it in conjunction with a stimulant laxative, a 2015 Cochrane review of palliative patients with constipation did not demonstrate any difference in efficacy between the surfactant docusate in combination with the stimulant sennosides, as compared to placebo plus sennosides.[27,28] Surfactants work by decreasing the surface tension of stool, allowing for increased water and fat absorption, which in turn leads to softer stools. Onset may take up to 3 days, but while stool may become softer, surfactants do not induce laxation. Advantages include a low side-effect profile, though fecal soiling may occur. Examples of surfactant laxatives include:

- *Docusate sodium*: 50–300 mg 2 times a day with a full glass of water
- *Docusate calcium*: 240 mg/day
- *Castor oil*: In general, not recommended in the palliative population due to common side effects of nausea and vomiting[29]

Osmotic Laxatives

Osmotic laxatives are indicated for moderate to severe constipation and are additionally used as bowel preparation for colonoscopy. These laxatives are nonabsorbable sugars that have an osmotic effect in the intestines, pulling fluid into the lumen and resulting in softened stool, bowel distension, and increased peristalsis.[29] Osmotic laxatives should be avoided in patients with suspected or known partial or complete bowel obstruction. Adverse effects are common and include abdominal cramping from increased peristalsis. Fluid and electrolyte abnormalities may also result, and laxatives containing magnesium should be avoided in patients with renal dysfunction, while laxatives with sodium should be avoided in patients with congestive heart failure, hypertension, and edema.[29] Some examples of osmotic laxatives include:

- *Polyethylene glycol (PEG)*: 17 g once to twice daily mixed with 4–8 ounces of liquid, with onset of action in 1–4 days. PEG has been shown to be superior to lactulose and safe when used up to 12 months.[29] PEG is a preferred option in palliative care, given that it is not absorbed systemically or metabolized by gut bacteria, resulting in fewer adverse effects.[29] Additionally, studies suggest superiority in stool frequency over lactulose for patients with chronic constipation.[29]
- *Lactulose*: 15–30 mL up to every 6 hours, maximum of 60 mL/day. This is a hyperosmotic laxative with frequent side effects of flatulence, nausea, and abdominal pain. The sweet taste may make it intolerable to some patients, and it can result in rebound diarrhea. Onset is typically within 24–48 hours. Although this may be considered in the palliative population, it is not first-line, and additional studies for the safety and efficacy in this population are needed. Use with caution in diabetics due to risk of hyperglycemia.
- *Sorbitol*: 30–45 mL of 70% solution once a day. This is another hyperosmotic laxative that is less expensive and less emetogenic than lactulose. Use with caution in patients with diabetes, cardiopulmonary issues, or renal disease due to risk of hyperglycemia and fluid or electrolyte imbalance.[29] As with lactulose, there is minimal evidence regarding sorbitol use in the palliative population.
- *Magnesium*: Magnesium is a component of many saline laxatives, which are sometimes used for acute evacuation due to rapid onset, typically within 1–6 hours. Use should be limited due to increased risk of electrolyte abnormality. Examples include magnesium citrate 150–300 mL, magnesium hydroxide (milk of magnesia) 15–30 mL, and magnesium sulfate 15 g dissolved in water.
- *Sodium phosphate*: 4–8 g dissolved in water. Electrolyte abnormality is again a risk, limiting its use in the palliative population.

Stimulant Laxatives

Stimulant laxatives are commonly used in moderate to severe constipation and in OIC. They function by stimulating the submucosal and myenteric plexuses and causing mucosal irritation, both of which increase peristalsis and fluid secretion into the gut.[30] Due to strong peristaltic activity, abdominal cramping is a common side effect. Lower doses given more frequently may help prevent this.[30] Although there is hypothetical risk of disrupting normal bowel function with frequent use, the evidence for this is limited and may be irrelevant in the palliative population.[25] Some examples of stimulant laxatives include:

- *Bisacodyl*: 5–15 mg/day, taken with food to avoid gastric irritation. Bisacodyl is part of the diphenylmethane family and acts on the small and large intestines with time of onset typically 6–12 hours.[30] Should not be taken within one hour of consuming antacids or dairy products, which can affect absorption. Bisacodyl suppositories will be discussed later.
- *Sennosides (senna)*: 8.6 mg, 2 tablets at bedtime to start; may titrate up to 4 tabs twice a day. Derived from a plant, and part of the anthraquinone family, with action on the large bowel only.[30] Time of onset is 6–12 hours.[30] Of note, a 2015 Cochrane review did not demonstrate any difference in efficacy between lactulose and sennosides,[27] with sennosides being better tolerated and less expensive.

Lubricant Laxatives

These laxatives lubricate and soften stool for easier passage. They are sometimes used to prevent straining in certain populations (e.g., recent surgery, hypertension). Mineral oil 5–30 mL at bedtime on an empty stomach is one example, with onset of action in 2–3 days. However, lubricant laxatives are generally not recommended in the palliative population due to their significant side-effect profiles, including perineal irritation and pruritus, fecal soiling, possibility of malabsorption (especially oil-soluble vitamins and medications), and risk of aspiration lipid pneumonitis, especially in geriatric patients.[29]

Rectal Suppositories

Suppositories act as a lubricant and cause local irritation, which helps stimulate laxation. Due to patient and caregiver discomfort, these are not used first-line, but may be considered in patients without bowel movement for more than 3 days. They should be avoided in patients with neutropenia and thrombocytopenia due to risk of infection and bleeding.[16] Examples include:

- *Bisacodyl*: 10 mg/day, retain 15–20 minutes. Onset for suppository is faster than when used orally, typically 20 minutes to 3 hours, with average of 1 hour.[30]
- *Glycerin*: 2 g daily, retain 15–60 minutes. May induce bowel movement within 15–60 minutes, and side effects are rare.

Enemas

As with suppositories, enemas should be avoided in patients with neutropenia and thrombocytopenia, and use is otherwise limited due to patient and caregiver discomfort. Many examples exist:

- *Warm tap water enema*: 200 mL retained rectally. May lead to bowel movement within 30 minutes. Often considered the safest enema option.

- *Milk and molasses enema*: Combine 6 ounces warm water with 3 ounces powdered milk, then add 4.5 ounces of molasses; place in enema bag and administer rectally, retaining as long as possible. Use up to 4 per day for severe constipation. Do not use in patients with lactose intolerance.[31]
- *Mineral oil enema*: 1 bottle daily as needed.
- *Soapsuds enema*: 200 mL retained rectally. May lead to bowel movement within 30 minutes. Generally not recommended due to risk of mucosal damage and infection.[29]
- *Sodium phosphate enema*: Not recommended in the palliative population; use extreme caution in patients with renal insufficiency due to risk of causing electrolyte abnormality.

Peripherally Acting Mu Opioid Receptor Antagonists

Peripherally acting mu opioid receptor antagonists (PAMORAs) represent a newer class of medication and function by blocking mu opioid receptors in the GI tract, leading to improved peristalsis. These are typically only used when other medications have failed or in severe OIC. Cost is a limiting factor. Common examples include[7,16]:

- *Methylnaltrexone*: 0.15 mg/kg administered subcutaneously. A fixed dose of 8 mg for patients weighing 38–62 kg and 12 mg for patients weighing more than 62 kg may improve ease of dosing.[19] Thirty percent of patients will have laxation within 30 minutes of injection, with 50% of patients having laxation by 4 hours. Up to 50% may not respond by 24 hours after the first dose, in which case a second dose may be given; otherwise, it is recommended every 48 hours as needed.[25] Methylnaltrexone is utilized particularly in patients with OIC with advanced illness who have failed first-line treatment and is superior to placebo in inducing laxation without increasing pain from central opioid withdrawal,[17] with a number needed to treat of 3.[7] Side effects include dizziness, nausea, abdominal pain, flatulence, and diarrhea. Although data are limited, it is avoided in patients with bowel obstruction due to risk of bowel perforation.[5] An oral version has also been approved, dosed as 450 mg once daily.[32]
- *Naloxegol*: 12.5–25 mg orally once daily, 1 hour prior or 2 hours after a meal. Naloxegol is oral naloxone that has been pegylated, which decreases passage across the blood–brain barrier in order to avoid centrally mediated opioid withdrawal while still antagonizing mu receptors in the gut.[20,33–35] Although a recent study for its use in patients with cancer-related pain was ended due to low enrollment, it is generally well-tolerated, with primarily mild GI side effects, and so may be considered in some palliative patients.[34] Naloxegol is contraindicated in patients with bowel obstruction and additionally in patients on vascular endothelial growth factor (VEGF) inhibitors.[35] May interact with medications that have strong CYP4503A4 inhibition activity.
- *Combination naloxone/oxycodone*: 40/20 mg, 60/30 mg, or 80/40 mg. There is evidence of improved bowel function without reversal of analgesia.[5]
- *Sustained-release naloxone*: Acts like a PAMORA through modification of the GI release mechanism of naloxone, resulting in reduced systemic concentrations. In healthy volunteers, GI transit after codeine was shortened after sustained-release naloxone compared to placebo. There are not currently any studies in the palliative population.[33]
- *Alvimopan*: 6–12 mg orally twice daily up to 7 days. Onset of action is 1 day, with number needed to treat of 5.[7] Alvimopan is currently only available through a special program for short-term use in patients hospitalized following bowel surgery and is not yet approved for OIC.[33] A single study showed a higher rate of myocardial infarction in the treatment group and has resulted in a black box warning, though this result has not been replicated in other studies.[33]
- *Naldemedine*: 0.2 mg/day by mouth. Recently approved for OIC in patients with chronic noncancer pain.[32]

Chloride Channel Activators

This family of medications functions by activating chloride channels in the gut, leading to increased fluid secretion and motility, which subsequently leads to softer stools and decreased GI transit time.[29] Indications include OIC, chronic idiopathic constipation, and irritable bowel syndrome. A common example is lubiprostone, which has been shown in randomized controlled trials to improve straining, abdominal bloating and discomfort, and severity of constipation compared to placebo, though without superiority in regards to dependence on rescue laxatives.[33] Typical dosing is 8–24 mcg orally twice daily with food, with time of onset 12–24 hours. Adverse effects include headache, diarrhea, and nausea. It is contraindicated in bowel obstruction[20] and is not recommended for patients on methadone, which interferes with chloride channel activation.[35] Although a promising option, there are currently no studies specific to the palliative or cancer population, and its cost may be prohibitive given that it is still under patent.[33]

Guanylate Cyclase-C Receptor Agonists

These medications also stimulate chloride channels, increasing fluid secretion into the gut lumen. They additionally decrease visceral hypersensitivity and so may have analgesic function.[20] Linaclotide is the first medication in this class and is approved for chronic idiopathic constipation and irritable bowel syndrome. Standard dosing is 145–290 mcg orally once daily 30 minutes before breakfast. It is well tolerated, with a number needed to treat of 5–8.[20] Plecanatide was also recently approved for chronic idiopathic constipation. In a randomized controlled trial of patients receiving 3 mg/day of plecanatide versus placebo, the treatment group was more likely to have improved frequency and consistency of stools, as well as less straining.[36] Both of these medications are contraindicated in bowel obstruction, and studies are still needed in the palliative population.

Serotonin Type 4 Receptor Agonists

There is evidence that the selective serotonin reuptake inhibitors (SSRIs) fluoxetine and citalopram improve straining, sensation of incomplete evacuation, and global symptoms in patients with irritable bowel syndrome. Although there are no studies specific to the palliative population, these might be considered for a patient with depression who is prone to constipation. Another serotonin agonist, prucalopride, is a prokinetic agent[20] that has been evaluated in OIC and chronic constipation, although it is not currently approved by the US Food and Drug Administration (FDA).[18] One advantage is a low potential for drug interactions,[20] although adverse effects include headache, abdominal pain, nausea, and diarrhea.[20]

Metoclopramide

Metoclopramide is a dopamine antagonist that at high doses also antagonizes serotonin[37] in the chemoreceptor trigger zone of the central nervous system, leading to its utility in treating nausea in patients on emetogenic chemotherapy. This medication also sensitizes tissues of the upper GI tract to acetylcholine, leading to a prokinetic effect that explains its use in gastroparesis, as well as the adverse effect of diarrhea. Because of this prokinetic effect, there are some clinicians who might consider using metoclopramide in treatment of constipation. While there is minimal evidence to support the use of metoclopramide specifically for treatment of constipation, in a patient with nausea prone to constipation, it would not be unreasonable to consider metoclopramide in lieu of more constipating HT-3 antagonists. Extrapyramidal side effects are a possibility, especially in older patients,[38] and the patient should be maintained on the lowest effective dose for the shortest time possible. It should be avoided in patients with complete bowel obstruction due to risk for abdominal cramping and bowel perforation.

Probiotics

Probiotics are substances that benefit a host by altering the balance of helpful to harmful microorganisms. There is evidence that administering lactobacillus in the nursing home population improves constipation, though there is no evidence for its use as prophylaxis or in lieu of standard laxatives.[29] In another study, patients with chronic idiopathic constipation had lower levels of Bifidobacterium and lactobacillus in the intestinal microbiome, and treatment with 5×10^8 and 9.7×10^{10} colonies, respectively, resulted in decreased stool transit time.[20] Probiotics might be considered for certain palliative patients, especially since side effects are similar to placebo; however, there is a lack of head-to-head trials with laxatives, and the ideal dosing and bacterial composition has yet to be determined.[20] Additionally, cost may be a limiting factor.

Case Study 1 (continued)

Mr. B has multiple risk factors for constipation, including advanced age, use of chemotherapy associated with constipation (paclitaxel), and increased opioid requirements. Exam shows mild abdominal distension but is otherwise benign. Two tablets of sennosides are initiated routinely at bedtime, in addition to polyethylene glycol daily as needed. One week later he is having daily bowel movements.

Malignant Bowel Obstruction

Case Study 2: A Patient with Ovarian Cancer

Ms. S is a 46-year-old woman with advanced ovarian cancer and multiple prior abdominal surgeries. She is currently on palliative chemotherapy, and unfortunately has developed acute-onset nausea, bilious emesis, and abdominal pain. She had a small, watery bowel movement last night. She has not been able to keep down any food or liquids for 3 days.

Definition and Prevalence

Malignant bowel obstruction (MBO) occurs when the flow of GI contents is interrupted due to involvement of malignancy. Approximately 3–15% of all patients with cancer will develop MBO.[40] It is most common in patients with gynecologic and GI cancers, with 25–40% of MBO cases arising from colon cancer, 16–29% from ovarian cancer, and 6–19% from gastric cancer.[41] To a lesser degree, obstruction can also develop in patients with metastatic breast, lung, melanoma, and pancreatic cancers. At times, MBO may be the presenting symptom of intraabdominal malignancy; for other patients, it may be the first sign of tumor recurrence.

Pathophysiology and Risk Factors

MBO occurs when intestinal intraluminal pressure is increased and a cycle of distension-secretion-distension develops.[42] This can occur as a result of functional obstruction related to nerve involvement (e.g., paraneoplastic neuropathy or tumor invasion of the myenteric plexus) or iatrogenic reasons (including medications like opioids and anticholinergics, which slow the gut). Mechanical obstruction is more common than functional obstruction and is caused by both intrinsic compression of the intestines (e.g., from intraluminal or intramural tumor growth) and extrinsic compression (e.g., from postsurgical adhesions, tumor mass, carcinomatosis, and radiation or chemotherapy-induced fibrosis). Obstruction may be partial or complete, unifocal or involving multiple areas of intestine. About 61% of MBO cases start in the small intestine, 33% in the large intestine, and 20% in both simultaneously.[40] Advanced age, male sex, multiple comorbidities, and weight loss are all risk factors for increased mortality.[41]

Assessment

History

History should begin with a review of the risk factors previously discussed, including use of medications that slow the gut (e.g., opioids and anticholinergics), as well as presence of prior intraabdominal surgery, radiation, or chemotherapy. A history of previous obstruction is important information as studies have shown that more than half of patients with resolved MBO later develop recurrent obstruction.[40]

History should also include a careful discussion of symptoms. The symptoms described may provide information on the location of the obstruction. For instance, in small bowel obstruction (SBO), abdominal pain is typically an early symptom in the peri-umbilical region. On the other hand, abdominal pain in large bowel obstruction (LBO) is often localized, intermittent, colicky, and occurs later in the obstructive process.[43] Nausea tends to be more prominent in SBO, with abundant, bilious emesis; nausea occurs less often in LBO, though when present, emesis may be foul-smelling and occur as a late symptom.[40,43] Abdominal distension occurs more often with distal obstruction and is less likely when obstruction is proximal or when tumor encases the bowel. Anorexia and dehydration are often present and occur more frequently in SBO due to nausea with emesis.[43] In many cases, patients with MBO have not had a bowel movement in the last 72 hours, though loose stools may continue to occur if obstruction is only partial. A patient may continue to have stools even 12–24 hours after complete obstruction occurs due to decompression of the distal bowel.[40]

Physical Examination

Abdominal examination is key in the evaluation of MBO and should include inspection for surgical scars and hernias, which indicate higher risk for obstruction. Extent of abdominal distension should be assessed, as well as the presence and location of tenderness. Percussion should be performed, with a tympanic sound more indicative of air, while a dull sound is more suggestive of other causes, such as ascites or stool. Upon auscultation of bowel sounds, a hyperactive "tinkling" sound or borborygmi may be present; or, in the case of paralytic ileus, bowel sounds may be absent completely.[44] Presence of palpable masses on abdominal exam, in addition to the presence of ascites and cachexia, are often indicative of inoperable MBO.

Rectal exam to exclude fecal impaction should be performed except when the patient has neutropenia or thrombocytopenia. The rectum may need to be first emptied with a suppository or enema prior to confirming a diagnosis of MBO.

Bowel perforation from MBO should be considered in a patient who appears clinically ill on exam with abnormal vital signs and evidence of sepsis.

Diagnostic Studies

Abdominal CT is the gold standard for diagnosing MBO, with high sensitivity and a specificity of greater than 90%.[40,45,46] In addition to confirming the diagnosis, CT provides information on the location of the obstruction by revealing a transition zone between flat and distended bowel. CT can demonstrate if obstruction is partial or complete and whether risk factors like carcinomatosis or adhesions are present. It can also rule out surgical emergencies like bowel perforation, volvulus, or strangulation.

Although CT is the gold standard, many clinicians will still obtain an abdominal x-ray as the first imaging study as it is quick and inexpensive. X-rays are often sufficient to exclude MBO in a lower risk patient, with a sensitivity of 50% and specificity of 75%.[40,45,46] MBO is suggested on abdominal x-ray by the presence of dilated loops of bowel and air–fluid levels.

Management

While numerous studies exist on the topic of MBO, they are often poor quality, with small participation and multiple confounding factors. As a result, there is a paucity of widely accepted guidelines on the management of MBO, and many clinicians will either follow locally established guidelines or no guidelines at all.[42] However, several common themes exist and are discussed below (Box 14.4).

Nursing Interventions and Supportive Care

Providing education and managing expectations is a critical part of any patient's care. Given the high morbidity and mortality associated with obstruction (patients with inoperable MBO typically have a prognosis in the span of weeks to months at most),[40] nursing and other clinical staff may consider the diagnosis of MBO as a "checkpoint" in a patient's progression of illness and an opportunity to reassess a patient's values and overall goals of care.[47] It is reasonable at this time to consider a discussion on the risks and benefits of hospice care, which focuses on QOL and does not preclude a patient with MBO from receiving supportive and pharmacologic management of symptoms. Providing information on the reasons for each intervention recommended and an honest discussion of the expected outcomes can help reassure patients they are receiving appropriate care and help them decide when the risks of an intervention are too high. Patients and families should also be informed that even when obstruction does resolve, there is unfortunately a high rate of recurrent obstruction.[48–50]

Patients who present with MBO are often placed *nil per os* (NPO) to help manage nausea, since anything taken orally will have no place to go. A small subset of patients with partial MBO may be able to tolerate sips of liquid, and good oral care can help relieve the sensation of thirst. Intravenous hydration is often initiated to correct dehydration, and electrolyte replacement, such as correction of hypokalemia, may help improve bowel motility.

Box 14.4 Suggested Algorithm for Management of Malignant Bowel Obstruction

Stage 1

- Place patient NPO
- Nasogastric tube to low intermittent suction (as indicated)
- Parenteral rehydration +/− electrolyte repletion
- Surgical and/or interventional consultation
- Antiemetic: Dexamethasone 8 mg IV/SQ daily plus haloperidol 1 mg IV/SC every 8 hours
- Antisecretory: Scopolamine 1.5 mg TD patch or glycopyrrolate 0.1 mg IV/SC every 6 hours
- Analgesia: Opioids as per WHO ladder, given IV/SC with or without PCA

Stage 2 (for inoperable patient, after 5 days of treatment)

- If obstruction is resolved: Stop corticosteroids and antisecretory medications
- If obstruction is not resolved: Reduce corticosteroids and antisecretory medications and start octreotide 200 mcg every 8 hours IV/SC for 3 days

Stage 3 (after 3 more days of treatment)

- If vomiting has stopped: Find lowest effective dose of octreotide
- If vomiting continues: Stop octreotide and consider endoscopic venting gastrostomy

Source: Adapted in part from Reference 68.

Nasogastric tube (NGT) decompression is a common early intervention in MBO and is most helpful for patients with SBO who suffer from abdominal distension with intractable nausea and vomiting. The NGT is placed to suction and removes gastric contents, resulting in improved symptoms. Sometimes, bowel rest and gastric decompression alone may result in resolution of obstruction without further intervention. When gastric output is less than 100 mL/day, the NGT can be clamped on a trial basis, then removed if symptoms remain stable. Expert consensus says that NGT should not be removed if output is more than 1 L/day.[51] At times, patients may be adamant that they do not want an NGT, and indeed these tubes can be uncomfortable while also increasing the risk of nostril and esophageal erosion, pharyngitis, sinusitis, and aspiration.[47] Allowing flexibility in treatment options is warranted for these patients who already have minimal control of their situation. For instance, some patients prefer dealing with nausea to having a NGT, while others prefer to utilize a NGT so they can continue to drink for gratification, with fluids subsequently removed through the NGT via suction.

It is worth noting that total parenteral nutrition (TPN) is sometimes offered to patients with MBO in hopes of improving nutritional status. In a very select population with preserved functional status, the possibility of response to chemotherapy, or those with a specific goal (e.g., make it to a daughter's wedding), this may be appropriate.[47] However, in general, TPN is not recommended for MBO patients with concomitant terminal cachexia and may actually worsen symptoms by contributing to ascites, worsening pleural effusions, increasing GI secretions, and causing metabolic abnormalities.[52]

Surgical Management

All patients with MBO warrant surgical consultation. The primary goal of surgery is reestablishing function of the GI tract, but up to 50% of patients with MBO are poor surgical candidates.[42] Rarely, surgery is required on an emergent basis for bowel perforation or ischemia, but in nonurgent situations, initial nonoperative management is often appropriate. There is no well-defined criteria for surgical candidacy in MBO, and surgeon comfort level and the patient's ultimate goals play a large role in decision to proceed. However, some general principles in determining poor candidacy for surgery include a less than 2-month prognosis, advanced age,[49] poor performance status and nutritional level, presence of ascites or adhesions, and carcinomatosis or multifocal obstruction.[46]

Surgical intervention can take many forms in a patient with MBO. When obstruction is related to adhesions, these can be lysed surgically. Tumor debulking may help minimize external compression on the intestines, and, in cases where there are minimal sites of obstruction, bowel resection with reanastomosis is often the best option for return of GI function. In other situations, intestinal bypass or creation of an ostomy can circumvent the site of obstruction. The morbidity of surgical intervention in MBO is 42%, and mortality ranges from 5% to 32%, with lower rates for ostomies and higher rates for small bowel resection.[48,49] Up to 50% of patients who undergo surgical intervention may later reobstruct,[48,49] which is important for patients to consider before undergoing a risky surgery. However, when successful, studies have shown that surgical intervention results in 32–100% palliation of symptoms, 45–75% chance of resuming a diet, and 34–87% chance of being discharged home from the hospital.[48,49] Surgical patients have been shown to have higher QOL and longer median survival following surgery (8–34 weeks) compared to those who receive conservative treatment (4–5 weeks),[46] though it is difficult to tell if these findings result from the effects of surgery itself or are related to the fact that patients who are surgical candidates are often healthier to begin with.

Before a patient agrees to surgery, he or she should have a clear understanding of the expected outcome. While some return to a regular diet, as previously mentioned, others, such as those with gastrostomy, may require a soft or liquid diet to facilitate drainage. Even for patients who are able to take food orally following surgery, they should be aware that surgical treatment of MBO is not expected to reverse weight loss and anorexia due to concurrent widespread metastatic disease.

Procedural Management

Procedural interventions can be considered for patients who either decline surgery or are not candidates. These patients typically have a prognosis in the range of 2–6 months. One of the most common procedures performed for patients with MBO is placement of a venting gastrostomy, which can be performed by surgeons, gastroenterologists, or interventional radiologists. In this situation, the patient's gastrostomy is typically placed to low intermittent suction, taking the place of NGT decompression. Venting gastrostomy is indicated for nonsurgical patients who have received significant symptomatic benefit from NGT decompression.[53–55] Complications include leakage around the insertion site, skin irritation and infection, gastric bleeding, peritonitis, and tube blockage, which may necessitate multiple visits to the emergency room. In spite of this, many patients find a gastrostomy less intrusive and more comfortable than a NGT. Portal hypertension, ascites, and carcinomatosis are relative contraindications for placement of gastrostomy due to risk of poor healing; patients with high bleeding risk may also be excluded.[53–55] It is important to educate the patient, family, and even other staff involved in the patient's care that, in this situation, the purpose of the gastrostomy is for gastric decompression to relieve symptoms and is not intended for enteral nutrition or expected to improve nutritional status. However, for patients who desire food for oral gratification, venting gastrostomy may allow the opportunity to enjoy the taste of food, modified for elimination by the tube.

Self-expanding stents are another procedural intervention that can benefit patients with unifocal obstruction, especially in the esophagus, duodenum, or colon. Technical success rate is high, and obstruction is relieved 83–100% of the time.[56,57] Complications include stent migration (8.5–12.4%), as well as intestinal perforation (0.5–4%), for which patients on anti-angiogenic medications or concurrent radiation are at higher risk.[56,57] As with surgical interventions, patients should be aware that their diets following stent placement may not return to normal, but instead they may require low-residue or liquid diets. Additionally, stents take several days to fully expand and may cause significant discomfort as they place pressure against tumor mass. Some patients needing upper endoscopy for stent placement require general anesthesia and intubation, and, in patients with poor performance status, it should be realized that extubation following the procedure may be challenging. Stenting of the lower GI tract tends to be more straightforward, and studies have shown improved QOL for patients who received stenting for colorectal obstruction as compared to similar patients who received surgery.[58]

Pharmacologic Management

Pharmacologic management is important to consider for patients with MBO unable to benefit from surgical or procedural interventions, and is the recommended approach for patients with prognosis of days to weeks or weeks to months according to NCCN guidelines.[47] Inoperable MBO may resolve in more than a third of patients receiving supportive and pharmacologic management alone.[40] Oral administration of medications is typically avoided in MBO due to risk of worsening nausea and poor absorption, so the intravenous (IV), subcutaneous (SC), intramuscular (IM), transdermal (TD), sublingual (SL), and rectal (PR) routes may play a role. Due to the overall poor quality of data available for pharmacologic management of patients with MBO, many of the medications are utilized off-label. Pharmacologic management can be summarized into three goals: reduce nausea, reduce intestinal secretions, and provide adequate pain relief.

Antiemetics

No studies exist that demonstrate benefit of one antiemetic over another in the treatment of obstruction. Steroids, neuroleptics, and serotonin (5-HT3) antagonists are examples of commonly used antiemetics in this situation.

- *Steroids*: There is conflicting evidence regarding the benefit of steroids in patients with MBO. Studies have suggested a trend toward resolution of bowel obstruction for patients receiving 6–16 mg of dexamethasone, with a low rate of side effects, although there is no evidence of survival benefit.[42] In general it has been difficult to compare steroid studies due to multiple confounding factors, including whether or not carcinomatosis was present, the level of obstruction, and if the patient was on chemotherapy. Additionally, most studies have been small and involve the use of multiple medications simultaneously. In spite of the limited evidence, many experts recommend a trial of steroids given the low steroid-related morbidity when used short term.[42,51] The theoretical mechanism involves reduction in bowel edema and inflammation, leading to decreased intrinsic and extrinsic pressure on the intestines, which in turn decreases distension and has an indirect analgesic effect.[59] Dexamethasone is typically the steroid of choice given lower mineralocorticoid activity, leading to less fluid retention. A dose of 6–16 mg IV/SC can be given once a day for a 3- to 5-day trial; expert consensus suggests using no longer than 10 days.[42] Another option is methylprednisolone 1–4 mg/kg/day.
- *Neuroleptics*: This family of medications decreases nausea by acting as central dopamine antagonists.[60] Many experts consider haloperidol a first-line option due to a lower rate of sedation and lower anticholinergic side effects compared to chlorpromazine.[51] Suggested initial dosing is 0.5–2 mg IV/SC every 8 hours as needed, with option to titrate up to 15 mg/day. For a patient at home, a trial of haloperidol liquid concentrate may be attempted sublingually. Although there is a risk of tardive dyskinesia and cardiac QT prolongation from haloperidol, this risk may be less relevant in the palliative population. A second neuroleptic is chlorpromazine 10–25 mg IV every 4–6 hours as needed. Metoclopramide 5–10 mg IV/SC every 8 hours, with titration up to 20 mg every 8 hours if needed, can also be considered, but with a caveat. While haloperidol and chlorpromazine affect central dopamine-2 receptors only, metoclopramide also affects peripheral dopamine-2 receptors, leading to a prokinetic effect.[59,61] For this reason, metoclopramide can be considered in patients with partial MBO without cramping, but in a patient with complete obstruction, it may paradoxically worsen abdominal pain and nausea, along with increasing risk for bowel perforation.[51]
- *5-HT3 antagonists*: Some studies have suggested that this family of medications may help control emesis when used in combination with dexamethasone.[62] They function by antagonizing 5-HT3 receptors centrally in the chemoreceptor trigger zone, as well as peripherally at the vagus nerve. Because constipation is a common side effect, these are generally not considered first-line in patients with ileus. However, they are otherwise well tolerated, though with headache being one of the more common side effects. One example is granisetron 1–3 mg/day IV. A second example is ondansetron 4–8 mg IV every 4–8 hours as needed, up to 24 mg/day. Patients in the home setting may benefit from a trial of ondansetron oral disintegrating tablet given sublingually due to ease of administration.

Antisecretory Agents

Medications that decrease GI secretions to assist in resolving MBO include anticholinergic medications, proton pump inhibitors (PPIs), histamine-2 (H_2) blockers, and somatostatin analogues.

- *Anticholinergics*: This is a large group of medications that have antiemetic effects on the vestibular center, as well as antispasmodic and antisecretory effects. This leads to reduced volume of GI secretions compared to placebo. Common side effects are dry mouth and urinary retention. Scopolamine is one option and can be administered 40–120 mg/day via continuous IV/SC infusion or more conveniently as a 1.5 mg TD patch, with the latter being a practical option in the home setting. Scopolamine is a tertiary amine and, as such, crosses the blood–brain barrier and places patients at a higher risk of delirium. Glycopyrrolate is another anticholinergic drug less studied in the palliative population,[63] but one still often used empirically due to lower risk of potentiating delirium, as it is a quaternary amine and crosses the blood–brain barrier less. Initial dosing is 0.1–0.2 mg IV/SC every 6 hours, up to a maximum of 0.8 mg/day.
- *PPIs and H_2 blockers*: Both were shown in a meta-analysis by Clark et al. to reduce gastric secretions and bile reflux in patients with inoperable MBO, with the H_2 blocker ranitidine acting to a greater degree than PPIs.[44] Options include omeprazole 20 mg SC twice a day, pantoprazole continuously or via 40–80 mg IV bolus daily, and ranitidine 50–150 mg IV twice a day.
- *Somatostatin analogues*: Somatostatin is a peptide hormone secreted by the hypothalamus and the gut, and it inhibits peripheral secretion of vasoactive intestinal peptide. This in turn decreases splanchnic and portal blood flow, reduces gastric secretions and GI motility, and increases GI water reabsorption and production of intestinal mucous, ultimately resulting in improvement of nausea and vomiting.[59,64] Octreotide is an analogue of somatostatin used for a variety of reasons in the palliative population. A 2012 review of 15 randomized controlled trials and observational studies involving 281 patients with inoperable MBO treated with octreotide showed a 60–90% therapeutic success rate.[65] A more recent 2016 review of seven randomized controlled trials was somewhat less conclusive but did suggest mild benefit compared to placebo.[66] Octreotide is typically not used first-line, at least in part due to cost, but it can be considered as first-line therapy in early recurrence of bowel obstruction for patients who have previously responded well to octreotide. Suggested initial dosing is 100–200 mcg IV/SC every 8 hours. Up-titration should be considered if gastric output is greater than 1 L/day, with maximum dose of 900 mcg/day. A depot version is available and can be given 30 mg IM every 28 days. Because the depot takes a week to reach steady state, it is recommended to continue giving the immediate-release form for 6 days after the depot was initiated.

Analgesics

Many clinicians may be wary of providing opioids to patients with MBO given the common side effect of decreased GI motility. However, obstruction often results in significant discomfort, and opioids are still the mainstay of treatment for the cancer patient with moderate to severe pain. There are no controlled trials comparing different opioids for the indication of MBO. Hydromorphone and morphine are often used due to wide availability, and patient controlled analgesia (PCA) is one route of administration that can allow patient control and easy titration. The oral route is not preferred for opioid administration as the patient is often unable to tolerate oral medications due to nausea and vomiting; additionally, if the patient has decompressive NGT or gastrostomy, it is unclear how much drug will actually be absorbed. Other routes to consider are IV and SC, though these may be challenging in the home setting, or PR, though this option may be less desirable to the patient and caregiver. TD fentanyl or buprenorphine can be convenient means of providing long-acting analgesia. TD fentanyl is sometimes preferred to other opioids due to less influence on GI motility and less constipation,[26] as well as better tolerance in patients who are dehydrated or have acute renal failure. Fast-acting fentanyl is also available as a nasal spray, sublingual spray, lozenge, and buccal tablets, but require Risk Evaluation and Mitigation Strategy (REMS) certification to prescribe. Both TD and fast-acting fentanyl are not appropriate in an opioid-naïve patient. Another option to consider for patients at home without IV access and with lower opioid requirements is morphine or hydromorphone oral concentrates. When given sublingually, each has a bioavailability of approximately 20%, which is often sufficient to provide pain relief in select patients with low opioid requirements.[67]

Case Study 2 (continued)

Ms. S is started on IV hydration and placed NPO. CT scan shows carcinomatosis and obstruction of the small bowel. Due to multiple sites of involvement, she is deemed not a surgical candidate and is instead started on dexamethasone 8 mg IV daily, scopolamine TD patch, and haloperidol as needed for nausea. She declines a nasogastric tube. Her abdominal pain is able to be controlled with a fentanyl patch and concentrated sublingual liquid morphine. Her goals of care are discussed, and, given her desire to focus on QOL, she is transitioned home with hospice care.

Diarrhea

Case Study 3: A Patient with Metastatic Colon Cancer

Ms. P is a 54-year-old woman with metastatic colon cancer on 5-fluorouracil and oxaliplatin chemotherapy who was recently hospitalized for pneumonia. She now presents with 8–10 loose, nonbloody bowel movements per day, accompanied by mild abdominal cramping.

Definition

Diarrhea is defined as stool that is abnormally loose, with decreased consistency and/or increased frequency or volume.[69] It is defined more specifically by the World Health Organization as more than three watery bowel movements per day.[70] Diarrhea is considered acute when present for less than 14 days, subacute or persistent between 14 and 30 days, and chronic when present for greater than 30 days.

Prevalence and Impact

Although not as common as constipation, affecting less than 10% of patients admitted to the hospital or palliative units,[71] diarrhea still has a significant effect on many patients receiving palliative care, as well as an impact on utilization of healthcare resources.[72]

Physical Impact

In terms of physical impact, a patient may suffer from dehydration, electrolyte disturbances, malabsorption, and weight loss. Perianal skin breakdown, ulcers, and hemorrhoids often occur concomitantly and increase discomfort, especially in the bedbound patient. The need to frequently evacuate often leads to poor sleep, with subsequent fatigue and drowsiness.

Diarrhea is also associated with increased morbidity and mortality and can even be fatal when untreated in patients on chemotherapy.[69,70]

Medication Adherence

From a treatment standpoint, iatrogenic diarrhea may lead to poor adherence to treatment regimens. For patients with diarrhea related to chemotherapy, the dose may be reduced, delayed, or even discontinued altogether, which can affect prognosis. HIV patients with diarrhea related to antiretroviral therapy (ART) may take their medications inconsistently, leading to increased viral resistance and putting them at risk for opportunistic infections.

Psychological Impact

Perhaps less well appreciated is the psychological impact that diarrhea can have. Patients may have anxiety about frequent restroom visits or soiling themselves, which can discourage them from social interaction, leaving the home, or participating in sexual activity. Persistent diarrhea has been associated with decreased QOL in the palliative population.[72] Recognizing how diarrhea can affect a patient's QOL can help care providers offer empathy and support to their patients.

Pathophysiology and Risk Factors

Diarrhea can be broken down into various categories, including osmotic, secretory, exudative, motility-associated, and functional. However, because most diarrhea is related to a combination of these classifications,[70,71] it may be easier to group by associated causes and conditions.

Infection-Related Diarrhea

Bacterial and Viral Enterocolitis

Most acute cases of diarrhea in both the general and palliative populations are related to viral enterocolitis and are self-limited.[69] Bacterial enterocolitis from *Salmonella, Shigella, Campylobacter*, and *Escherichia coli* can similarly occur in both the immunocompetent and immunocompromised host via spread by contaminated food or water.

Opportunistic Infection-Related Diarrhea

Many patients in the palliative population are immunocompromised, including patients with AIDS, malignancy, or patients on immunosuppressive treatments or chemotherapy, placing them at risk for diarrhea from opportunistic infections. Viral causes include herpes simplex virus, as well as the most common viral cause of diarrhea in patients with AIDS, cytomegalovirus. Cytomegalovirus infection often results in colitis with symptoms of rectal bleeding, abdominal pain, fever, and weight loss.[73] Parasitic opportunists may also cause diarrhea, including *Cryptosporidia, Microsporidia, Giardia lamblia*, and *Entamoeba histolytica*. In the severely immunocompromised, *Mycobacterium avium* complex is another cause of diarrhea.

AIDS-Related Diarrhea

In patients with AIDS, the prevalence of diarrhea at end of life is 6–54%.[70,73] Historically, this has been related to opportunistic infections such as those mentioned previously, especially in patients with $CD4^+$ T-cell counts under 200 cells per mm^3. In recent years, however, as use of ART has improved, the proportion of noninfectious-related diarrhea has increased. Diarrhea related to side effects of ART itself may represent up to 19% of diarrhea complaints and is thought to result in part from protease inhibitor-induced apoptosis of the GI epithelium.[73] Another noninfectious cause is HIV enteropathy, which is a distortion of the GI architecture caused by the HIV virus itself that results in malabsorption and weight loss.[73] HIV enteropathy may occur in both acute HIV and in advanced AIDS.

Cancer-Associated Diarrhea

In patients with advanced cancer, the prevalence of diarrhea is approximately 7–10%.[70] For some, diarrhea may be related to effects of the cancer, such as secretory diarrhea in carcinoid syndrome, diarrhea from malabsorption in patients with pancreatic insufficiency from pancreatic cancer, or in cases of rectal cancer. For other patients, diarrhea is related to cancer treatment, including secretory diarrhea in patients with GI graft versus host disease following stem cell transplant. Radiation-induced secretory and/or exudative diarrhea is also common and can occur either acutely or as a late effect of treatment. This is most common in patients receiving radiation to the pelvis and is dose-dependent.

Chemotherapy-induced diarrhea is worth discussing in more detail, as some randomized controlled trials have shown a frequency of severe diarrhea of up to 47%.[74] Many chemotherapies work by targeting rapidly dividing cancer cells but unfortunately also affect the rapidly dividing cells of the GI epithelium. This leads to mucositis with resultant secretory and hypermotile diarrhea.[74] Chemotherapy can also alter the normal intestinal microbiota, making a patient prone to infectious diarrhea.[75]

The severity of chemotherapy-related diarrhea is directly correlated to dose, with 22% of patients requiring dose reduction, 28% requiring dose delay, and 15% requiring discontinuation of treatment.[75] 5-fluorouracil represents a common cause of diarrhea, with grade 3–4 symptoms in 32% of patients on bolus therapy and 6–13% of those on infusion therapy.[74,76] In clinical trials, 1–5% of these patients even die from complications of 5-fluorouracil–induced diarrhea.[74,76] Irinotecan is another common culprit, with total incidence of 60–90%,[77] including 16–22% with grade 3–4 symptoms.[76] Up to 50% of patients on tyrosine kinase inhibitors develop diarrhea.[74] Some additional examples are provided in Box 14.5.[74–77]

Box 14.5 Examples of Cancer Medications Associated with Diarrhea

- 5-fluorouracil
- Cisplatin
- Cytosine arabinoside
- Hydroxyurea
- Interferon
- Irinotecan
- Monoclonal antibodies
- N-phosphonoacetyl-L-aspartate
- Nitrosourea
- Oxaliplatin
- Topoisomerase inhibitors
- Tyrosine kinase inhibitors

Iatrogenic Causes of Diarrhea

Just as with chemotherapy, sometimes clinical treatments provided to patients in palliative care can result in diarrhea as a side effect. The most common cause of diarrhea in patients with advanced illness is erratic laxative use.[71] A patient with constipation may use high doses of laxatives, with resultant rebound diarrhea. Antibiotics are another frequent cause of diarrhea, both as a direct side effect as well as by affecting the intestinal microbiome and placing patients at risk for secondary infection. *Clostridium difficile* (*C. diff*) is a bacterial infection that commonly occurs in patients taking antibiotics or spending time in healthcare facilities. *C. diff* results in pseudomembranous colitis and, in severe cases, can even lead to toxic megacolon.[73] Antacid use is also associated with diarrhea. Finally, surgery can be an iatrogenic cause of diarrhea, such as secretory diarrhea in a patient with short gut syndrome following bowel resection or hypermotile diarrhea in a patient with ileal resection or colectomy.

Additional Causes of Diarrhea

- *Malabsorption*: Lactase insufficiency (including temporary deficiency following acute viral enterocolitis) can result in osmotic diarrhea, and biliary or pancreatic problems can lead to fat malabsorption with resultant hypermotile diarrhea.
- *Fecal impaction with overflow*: More than half of elderly patients without cancer in the hospital have diarrhea due to fecal impaction with overflow diarrhea.[71]
- *Partial bowel obstruction*: Patients with partial bowel obstruction may additionally have overflow diarrhea.
- *Ingestion of hyperosmolar products* (e.g., sugary fruit drinks) may result in osmotic diarrhea.
- *Enterocolic fistula* may result in osmotic diarrhea.
- *GI hemorrhage* may result in osmotic diarrhea.
- *Inflammatory bowel disease*.
- *Functional diarrhea and irritable bowel syndrome*.

Assessment

History

Given a wide variation in normal bowel habits, it is first important to elucidate the patient's "usual" bowel routine. Details to assess include the quantity, frequency, color, and consistency of stools, as well as the timing of episodes in relation to oral intake or medication use.[69] It is useful to determine if the patient has high intake of fiber, lactose, or alcohol because all of these can contribute to diarrhea. The presence of anorexia can help determine the severity of the situation. Symptoms of fatigue, tenesmus, and nocturnal episodes should also be assessed. Concerning symptoms include the presence of blood or mucous in the stool and associated fever, weight loss, and severe abdominal pain or cramping. As with all patient histories, past medical history and medication use should also be discussed, with careful attention to prior GI surgeries, recent antibiotic use or hospitalization, and sick contacts.

The National Cancer Institute has developed a Common Toxicity Criteria to better define the severity of diarrhea by grades 1 through 5, with 1 being most mild (Box 14.6).[74]

Box 14.6 National Cancer Institute Common Toxicity Criteria[74]

- Grade 1: 2–3 more bowel movements (BMs) per day over baseline, or mild increase in stoma output.
- Grade 2: 4–6 more BMs per day over baseline, or moderate increase in stoma output, in addition to moderate cramping or nocturnal stools.
- Grade 3: 7–9 more BMs per day over baseline, incontinence, or severe increase in stoma output, in addition to severe cramping or nocturnal stools; symptoms interfere with activities of daily living.
- Grade 4: More than 10 BMs per day over baseline, grossly bloody diarrhea, need for intravenous hydration.
- Grade 5: Death.

Source: Reference 74.

Physical Examination

Vital signs should be assessed, including orthostatic measurements of heart rate and blood pressure, to help determine if hypovolemia is present.[78] Other signs of dehydration to notice are decreased skin turgor, pallor, and delayed capillary refill. If the patient is found to have an abnormal temperature, this may be more indicative of infectious causes.

Abdominal examination should include visual inspection for surgical scars and distension. Presence of tenderness, rebound tenderness, and guarding should be determined. The examiner should also palpate for masses, hepatosplenomegaly, and ascites, which may provide information about risk factors or possible etiologies.[78] Patients with ostomies should have these examined for functionality and leakage.

Assuming the patient does not have neutropenia or thrombocytopenia, a rectal exam should be performed to rule out fecal impaction as this is a common cause of overflow diarrhea. Assessing for competence of the external sphincter is also useful as lack of competency may explain incontinence. Presence of bloody stool is a more concerning sign. The perineal skin should be examined for presence of skin breakdown, hemorrhoids, and fissures as these contribute to patient discomfort.

Diagnostic Studies

Most cases of acute diarrhea do not warrant laboratory testing. In some situations, however, blood tests may provide helpful information. A complete blood count will determine if anemia or thrombocytopenia are present, indicating possible bleeding risk, and leukocytosis may suggest an infectious or inflammatory condition. Blood cultures should be considered for patients with fever or who appear clinically ill. Assessing electrolytes and renal function can help determine degree of dehydration and prerenal dysfunction. In select situations, elevated C-reactive protein suggests an inflammatory state, and liver function, glucose level, and thyroid-stimulating hormone may provide useful information on risk factors and etiologies of diarrhea. For a patient with HIV, the viral load and the $CD4^+$ T-cell count help determine risk for opportunistic infectious causes of diarrhea, especially when the $CD4^+$ T-cell count is less than 200 cells per mm^3.

Treatment of diarrhea is often performed empirically, and stool studies are reserved for more complicated situations, including persistent symptoms, severe illness, or high-risk patients. Enzyme immunoassays or polymerase chain reaction tests for toxigenic *C. diff* are perhaps some of the most useful stool studies as treatment is quite specific if the result is positive.[78] Checking for fecal occult blood and fecal leukocytes may help diagnose inflammatory causes of diarrhea. Stool bacterial cultures are rarely helpful in the setting of acute diarrhea and are typically reserved for situations where a positive test will change the patient's management.

Imaging studies are often not necessary in the evaluation of diarrhea. However, a CT of the abdomen is indicated when there is presence of guarding or rebound tenderness on exam and may help detect evidence of enterocolitis, bowel perforation, diverticulitis, pancreatitis, or abscess. Abdominal x-rays are usually low yield.

In severe, persistent cases of diarrhea, further investigation can be performed via sigmoidoscopy, colonoscopy, or endoscopy. These studies allow a visual assessment of the intestinal walls, as well as the opportunity to biopsy for signs of inflammation or infectious causes like cytomegalovirus or *C. diff*. However, these procedures should be avoided in patients with neutropenic enterocolitis, those with high risk of bowel perforation, or those in whom goals of care preclude invasive procedures.[78]

Management

Prevention

Certainly prevention is always superior to treatment. Unfortunately, while multiple studies have evaluated options to prevent diarrhea related to chemotherapy or radiation (e.g., probiotics, celecoxib, absorbents, and activated charcoal), supporting evidence is lacking.[74,76] The best prevention for infection-related diarrhea is good hand hygiene to avoid spread.

Nursing Interventions and Supportive Care

Patients and families should be educated about the causes and treatments for diarrhea. When a patient will receive chemotherapy with high risk for diarrhea, they should be aware of this side effect ahead of time and know when to contact their healthcare providers. It is important to consider that patients may be wary of notifying their healthcare team about diarrhea as they may fear it will exclude them from continuing chemotherapy. However, it should be stressed that providers be informed of symptoms early on in order to help treat them. Serious symptoms indicating a need for hospitalization include severe diarrhea (grade 3–4), significant nausea and vomiting, fever, sepsis, neutropenia, bleeding, inability to eat, and severe cramping. In some cases, a dose reduction or break in therapy may help with chemotherapy-related diarrhea,[47] but "drug holidays" are not recommended for HIV patients with ART-related diarrhea.

Beyond education, other supportive interventions include access to equipment (e.g., bedside commode or bedpan) to improve convenience when frequent diarrhea would otherwise cause several trips to the bathroom. Teaching and assisting in good skin care is key, with appropriate cleaning and drying to limit skin irritation related to moisture, as well as use of barrier creams to reduce skin breakdown.

Dietary recommendations are also helpful. Food triggers should be avoided, including those that are gas-forming.[69] Common foods to avoid include dairy products, caffeine and alcohol, foods with high sugar or sorbitol, high-fiber legumes (raw vegetables), high-fat foods, spicy meals, and high-risk foods (e.g., raw foods, food left out, food from street vendors). Instead, patients should increase bulk in their food by including psyllium, bran, or pectin. Eating frequent, small meals is preferred to a few large meals.

It is important for the patient with diarrhea to stay well hydrated. They should attempt frequent sips of clear liquids as tolerated and can consider oral rehydration solutions with sodium chloride and sugars, like sports drinks or soups. A good goal is 8–10 large glasses of clear liquids per day,[76] though this may be challenging in the palliative population. For patients with severe diarrhea and dehydration, parenteral hydration or subcutaneous hypodermoclysis may be helpful. In that situation, electrolyte repletion (e.g., magnesium, calcium, and phosphate) can also be considered.

Pharmacologic Management

Opioid Agonists

For patients who fail conservative management of diarrhea, opioid agonists represent the first-line pharmacologic option for symptomatic relief. These function by binding and agonizing peripheral opioid receptors in the gut, resulting in decreased peristalsis, increased water reabsorption, and promotion of fecal continence, all of which improve diarrhea.[69–71] Side effects include ileus, constipation, abdominal cramping, irritability, drowsiness, and dizziness.[75] Some common examples are discussed here.

- *Loperamide*: 4 mg by mouth initially, followed by 2 mg after each loose stool, up to 16 mg per day; titrate until diarrhea-free for 12 hours. Loperamide is generally used as the first medication in symptomatic treatment and is available without a prescription. It should be tried prior to diphenoxylate due to less crossing of the blood–brain barrier, with a subsequent lower risk of delirium. It is additionally less sedating than codeine. Its use should be avoided if there is blood in the stool or suspected *C. diff* infection.
- *Diphenoxylate/atropine*: 2.5 mg/0.025 mg, 1–2 tabs by mouth every 6 hours as needed, up to 20 mg/0.2 mg per 24 hours. This is a combination medication, with diphenoxylate working as a peripheral opioid agonist and atropine functioning as an anticholinergic, which together help to diminish GI secretions and decrease peristalsis.[69] Onset of action is 45–60 minutes.
- *Tincture of opium*: 0.7 mL by mouth every 4 hours, titrate to effect.
- *Codeine*: 10–60 mg by mouth every 4 hours as needed. As previously mentioned, sedation is a common side effect.

Adsorbent Agents

Adsorbent agents function by adding bulk to stool, binding bacterial toxins, and binding fluid, all which improve stool consistency.[73] Bismuth subsalicylate is a common example, and it additionally possesses an anti-inflammatory and mild antimicrobial effect. This is often utilized in acute diarrhea and can be administered as 30 mL liquid or two tablets by mouth every 30 minutes as needed, up to 8 doses per day.[69] Methylcellulose and pectin are other examples of adsorbent agents, the latter of which may take up to 48 hours to have effect.

Anticholinergics

As with atropine previously discussed in combination with the opioid agonist diphenoxylate, anticholinergics improve diarrhea by reducing GI secretions and decreasing peristalsis. Atropine is also used in combination with phenobarbital/hyoscyamine/scopolamine, 1–2 tablets every 6–8 hours as needed; this option may additionally improve abdominal cramping. Scopolamine alone administered via transdermal patch might also be considered in refractory cases, especially if nausea is concomitant.

Anti-inflammatories

The corticosteroid budesonide is occasionally used in chemotherapy-induced diarrhea refractory to loperamide. It can be given as 9 mg/day for 3–5 days.[74] Aspirin and indomethacin have been used to treat radiation-induced enteritis, although supporting evidence of efficacy is minimal. For patients with chronic diarrhea related to inflammatory bowel disease, mesalamine may provide relief.

Antisecretory Agents

Somatostatin is a peptide hormone secreted by the hypothalamus and the gut, and it inhibits peripheral secretion of vasoactive intestinal peptide. This is turn decreases splanchnic and portal blood flow, reduces gastric secretions and GI motility, and increases GI water reabsorption and production of intestinal mucous.[59,64] Octreotide is an analogue of somatostatin and is used for a variety of reasons in the palliative population. It can be used as first-line treatment in grade 3–4 chemotherapy-induced diarrhea or as a second-line treatment for grade 1–2 symptoms. Other indications include profuse secretory HIV-related diarrhea, high stoma output, or intractable diarrhea. Typical initial dosing is 50 mcg IV/SC every 8–12 hours, with titration of 100 mcg per dose every 48 hours up to 500 mcg every 8 hours. It can also be administered via continuous infusion at 10–80 mcg/hr, or as a depot injection of 20 mg IM once a month.[69] Some studies have examined whether octreotide can play a role in prophylaxis of diarrhea related to chemotherapy or radiation, and, while the evidence at this time is limited,[79] the depot may play a better role in prophylaxis than the immediate-release preparation.[80]

Ranitidine is a histamine-2 antagonist that reduces GI secretions and may help in cases of diarrhea related to fat malabsorption from pancreatitis or in patients with Zollinger-Ellison syndrome.[71]

Crofelemer is an antisecretory agent that represents the only FDA-approved therapy for symptomatic relief of noninfectious diarrhea in patients with HIV on ART.[73]

Microbial Agents

Antibiotics occasionally play a role in the treatment of diarrhea in palliative medicine. Just as in the general population, a patient with severe acute bacterial diarrhea, or "traveler's diarrhea," may benefit from azithromycin or a fluoroquinolone. Metronidazole or oral vancomycin are indicated for patients with diarrhea related to *C. diff* infection.

Probiotics are live microorganisms that are administered in hopes of reestablishing a healthy gut microbiome by competing with pathogenic microorganisms that cause infection. There is some evidence of probiotic efficacy in preventing antibiotic-induced diarrhea (e.g., *C. diff*), though the optimal strain and dosing are unclear.[77,81] There have additionally been efforts made to determine whether probiotics can prevent diarrhea associated with chemotherapy or radiation, but unfortunately their use for this reason is controversial due to lack of convincing evidence.[77,81] However, probiotics are generally well tolerated and so might be considered in a select population.

Other Antidiarrheal Options

Additional medications can be considered for specific causes of diarrhea. For instance, patients with diarrhea related to pancreatic insufficiency may benefit from 30,000 international units of pancreatic lipase with each meal, in combination with a low-fat diet. Lactase supplements will assist with diarrhea related to lactase deficiency. Bile acid sequestrants (e.g., cholestyramine) can sometimes reduce output in radiation-induced colitis or in steatorrhea from bile acid malabsorption. Alpha-2 adrenergic agonists (e.g., clonidine) are occasionally used for diarrhea related to opioid withdrawal. One case report showed resolution of octreotide-resistant diarrhea following the anticholinergic glycopyrrolate in a patient with neuroendocrine tumor.[82] Finally, the antihistamine cyproheptadine can assist in diarrhea related to carcinoid syndrome.[71]

Case Study 3 (continued)

Given Ms. P's recent hospitalization, her stool is checked for *C. diff* infection and returns negative. Her 5-fluorouracil, which commonly causes diarrhea, is switched from bolus to continuous dosing, and she is recommended to start loperamide 4 mg initially, followed by 2 mg every 4 hours as needed for loose stool. Her vital signs remain stable, she is able to maintain hydration through frequent sips of oral rehydration solution, and her stools decrease to twice per day.

Ascites

Case Study 4: A Patient with Alcoholic Cirrhosis

Mr. N is a 65-year-old man with alcoholic cirrhosis who develops weight gain, increasing abdominal girth, and yellowing of the skin. He now reports early satiety and has discomfort breathing when lying flat.

Definition

Ascites is an abnormal collection of fluid within the intraperitoneal cavity. There are multiple etiologies of ascites, but, regardless of the cause, it often results in significant discomfort and diminished QOL.

Prevalence and Pathophysiology

The etiology of ascites can be broken down into conditions associated with portal hypertension, peritoneal disease, and hypoalbuminemia.

Portal Hypertension

Portal hypertension is a condition of resistance to portal blood flow due to either structural changes in organs involved or due to dynamic changes affecting the velocity of blood flow. In either case, the end result is buildup of pressure with increased vascular permeability and resultant accumulation of fluid in the intraperitoneal space. Liver cirrhosis is the most common cause of ascites related to portal hypertension and represents 81% of all patients with ascites.[83] Nearly half of patients with cirrhosis develop ascites.[84] Of those with cirrhosis who develop ascites, 2-year mortality decreases to 50%.[85] When ascites becomes refractory to medical therapy, mortality is 50% within only 6–12 months.[85]

Other common causes of portal hypertension that can lead to ascites are:

- *Heart failure*: Represents 3% of patients with ascites [83]
- *Hemodialysis-associated (nephrogenic)*: Represents 1% of patients with ascites [83]
- *Liver metastases*
- *Portal vein thrombosis* (prehepatic resistance to portal blood flow)
- *Budd-Chiari syndrome* (posthepatic resistance to portal blood flow)

Peritoneal Disease

When the peritoneum is damaged, lymphatic drainage is impaired and vascular permeability increases. This results in accumulation of fluid within the peritoneal cavity.[86] Malignancy with peritoneal carcinomatosis is a common cause of this and represents roughly 10% of all patients with ascites.[83] When ascites is present in a patient with malignancy, it often signifies a poor prognosis in the range of 1–4 months, with the exception of ovarian and breast cancer, which have better prognoses.[86] For this reason, the development of ascites in a patient with cancer is often an appropriate time to readdress a patient's goals of care. Tuberculosis can also damage the peritoneum and represents about 2% of patients with ascites.[83]

Hypoalbuminemia

Conditions resulting in hypoalbuminemia also place a patient at risk for development of ascites primarily due to loss of oncotic pressure within the cardiovascular system, which leads to increased vascular permeability and again results in increased fluid in the peritoneal cavity. Therefore, nephrotic syndrome, severe malnutrition, and protein-losing enteropathies can all increase a patient's risk of developing ascites.[83]

Assessment

History

A patient presenting with ascites should be questioned about medication use and past medical history, including presence of any of the conditions discussed in the pathophysiology section. Additionally, risk factors for liver or infectious disease should be assessed, including a history of heavy alcohol use, hepatitis, hepatocellular carcinoma, or travel to tuberculosis-endemic regions.[87]

The hallmark symptom of ascites is abdominal distension, which patients might describe as their pants "fitting tighter." Patients may report weight gain and edema. Pain is often present, not only in the abdomen, but also in the pelvis or back due to carrying unaccustomed additional weight. Anorexia and early satiety may develop, as well as nausea and vomiting. Additional symptoms to review are presence of fatigue, dyspnea and orthopnea, urinary frequency, and constipation.[88] A patient may describe reduced mobility and poor body image concerns as a result of their distended abdomen and associated weight gain.[89] In patients with liver disease, concomitant pruritus may be present due to hyperbilirubinemia or confusion related to hepatic encephalopathy.

Physical Examination

It is challenging to diagnose ascites by physical examination alone, especially in a patient with obesity.[87,88] However, a thorough abdominal exam is still warranted, including assessment for distension and hepatosplenomegaly. The abdomen should be percussed and may result in a dull tone over the flanks in comparison to the tympanic sound more often present in bowel obstruction. Of note, at least 1.5 L of fluid must be present to appreciate dullness to percussion, and this in combination with bulging flanks yields a 75% sensitivity and 57% specificity in the diagnosis of ascites.[87] Dullness to percussion may also shift as the patient changes from the supine position to lateral decubitus, and this sign is more predictive of ascites than presence of a fluid wave.[87]

A cardiac exam should be performed, including observation for signs associated with heart failure, such as jugular venous distension, a third heart sound, pulmonary rales, and peripheral edema of the lower extremities or scrotum.

Presence of lymphadenopathy may be concerning for malignancy, and presence of inguinal or umbilical hernias may suggest increased intraabdominal pressure.

Examination should also include evaluation for the stigmata of liver disease, including visible changes (e.g., palmar erythema, spider telangiectasias, jaundice, scleral icterus, caput medusa, and gynecomastia), as well as neurologic changes (e.g., asterixis, encephalopathy).

Diagnostic Studies

The primary value of obtaining blood tests is to look for conditions that predispose to ascites. Presence of thrombocytopenia, elevated coagulation studies, elevated alanine aminotransferase (ALT) or aspartate aminotransferase (AST), alkaline phosphatase, and bilirubin all suggest liver dysfunction. Elevated creatinine and urea are suggestive of renal dysfunction,[87] and high brain natriuretic peptide (BNP) levels suggests heart failure. Electrolyte abnormalities such as hyponatremia can indicate volume overload. In severe malnutrition or nephrotic syndrome, albumin level is decreased.

Imaging Studies

Abdominal ultrasound is the first-line study in evaluation for ascites and can detect as little as 100 mL of ascitic fluid.[88] Not only will ultrasound help confirm the presence of ascites, but it will also determine the amount, and this can offer guidance during paracentesis.

On ultrasound as well as on CT, there may be evidence of a small, nodular liver if cirrhosis is present or evidence of liver metastases in the setting of malignancy. CT is often more helpful than ultrasound in determining overall disease burden in a patient with ascites related to cancer.[88]

Diagnostic Paracentesis and Laparoscopy

Any patient who presents with new-onset ascites warrants a diagnostic paracentesis to determine the cause.[83] The color of the ascitic fluid should be observed, with straw color common in liver cirrhosis, while bloody ascites may be more consistent with a traumatic tap or malignancy. In the past, testing whether the fluid was exudative versus transudative was often performed, with total protein concentrations of less than 1.5 g/L associated with a higher risk of spontaneous bacterial peritonitis.[87] However, this concept is now generally considered less helpful in diagnosis as compared to determination of the serum-ascites albumin gradient (SAAG). SAAG is obtained by subtracting the albumin level in the ascitic fluid from the serum albumin level. If the gradient is greater than or equal to 1.1 g/dL, there is a 97% chance of portal hypertension being present.[83] Lower gradients are more suggestive of malignancy, pancreatitis, or infection.

For a patient with suspected cancer, a positive cytology evaluation of the ascitic fluid is 100% specific for the diagnosis of malignancy. However, cytology is only 60% sensitive as not all tumors shed cells into the peritoneal space.[83] At times, checking for serum tumor markers such as alpha-fetoprotein levels for hepatocellular carcinoma or CA 19-9 for pancreatic cancer may be enlightening.

Infectious workup of ascites includes a microscopic analysis to rule out spontaneous bacterial peritonitis. Presence of more than 250 neutrophils per mm^3 is suggestive of infection.[90] Gram stain may quickly reveal information about the type of bacteria present, with a culture providing even more conclusive data. Leukocyte esterase strips are commonly used for analysis of urine but have also been found to have a sensitivity of 80–93% and specificity of 93–98% for diagnosing spontaneous bacterial peritonitis in the ascitic fluid.[87] If tuberculosis is suspected, checking adenosine deaminase activity or polymerase chain reaction for mycobacterium tuberculosis DNA are useful tests to consider.

Many additional studies exist, with common examples including amylase level for pancreatitis and triglyceride level for chylous ascites.

In some situations, diagnostic laparoscopy may allow for detailed visual examination of the intraperitoneal space to look for a cause of ascites, as well as the option to take tissue biopsies.[90] In the case of malignancy, this additionally allows the opportunity to perform surgical debulking.

Management

There are few randomized controlled trials that evaluate and compare various treatments for ascites. Most of the data available come from studies on cirrhotic ascites and, to a much lesser extent, from other causes, including malignancy.[89]

Nursing Interventions and Supportive Care

Because the presence of ascites in most situations indicates terminal illness, the goal of treatment is palliation of symptoms.[90] Nursing and clinical staff can provide education on dietary changes to minimize buildup of intraperitoneal fluid, including fluid restriction and sodium restriction (less than 2 g/day).[84] Good skin care remains important to prevent skin breakdown. Assisting with proper positioning additionally improves discomfort and dyspnea, and physical therapy can be considered to assist with mobility concerns.

Pharmacologic Management

Diuretics are commonly used in management of cirrhotic ascites. The use of diuretics in malignant ascites is more controversial, with studies showing a response rate of approximately 44%.[88] There are no well-studied dosing guidelines for diuretics for this indication, and typical dosing guidelines are followed.[89] Common examples of diuretics include potassium-sparing diuretics like spironolactone, which is an aldosterone receptor antagonist. Spironolactone is often considered a first-line treatment in cirrhotic patients, and it is sometimes considered for patients with malignancy who have a low chance of successful treatment with chemotherapy.[90] Doses used are 150–450 mg/day.[89] Loop diuretics like furosemide are also sometimes tried, though evidence of its utility for this indication is limited. Unfortunately, there is not a reliable way to predict which patients will benefit from diuretics,[91] and ascites is often refractory to pharmacologic management. Caution should be taken to ensure that the use of diuretics does not induce renal failure.

Other pharmacologic treatments to consider include chemotherapy for patients with chemosensitive malignancies, especially in ovarian and some GI cancers. Another possible option is octreotide, which in a single case series showed a reduction in ascites.[88]

Procedural and Surgical Management

Therapeutic Paracentesis

Therapeutic paracentesis is the first-line treatment for ascites refractory to supportive and pharmacologic interventions. This provides definite, albeit usually temporary, relief of symptoms and can be performed on an outpatient basis up to every 2 weeks.[85] In cases of cirrhosis, large-volume paracentesis can place a patient at risk for hypotension and renal dysfunction,[90] although patients with ascites from malignancy tend to have lower complication rates.[88] In fact, some studies have shown that removal of up to 5 L of fluid in patients with malignant ascites can be performed safely without resultant hypotension or need for IV fluids.[89] The patients with malignant ascites who benefit most from paracentesis are those who suffer from abdominal distention, dyspnea, anorexia, fatigue, insomnia, and decreased mobility; patients with severe pain at baseline tend to show less of a benefit.[92] Paracentesis includes rare but life-threatening side effects, including a 1% chance of significant bleeding and a 0.4% chance of small bowel perforation.[85]

Catheters

Patients requiring frequent paracentesis for symptomatic relief may benefit from an indwelling catheter for ease of fluid removal. Pigtail catheters are currently used only rarely due to 35% infection rate, 30% rate of blockage, and 20% rate of leakage.[86] A single-cuffed indwelling peritoneal catheter (e.g., PleurX or Rocket) is much more common and is indicated for patients with symptoms in spite of large-volume bimonthly paracentesis who are otherwise not candidates for transjugular intrahepatic portosystemic shunt (TIPSS) or peritoneovenous shunt (discussed in more detail later).[85,86] Patients with single-cuffed indwelling peritoneal catheters are typically drained 2–3 times per week in the home setting by a nurse or trained caregiver.[93] These catheters have a high rate of technical success, though with an increasing risk of infection the longer they are present, especially after 3 months. This option may preserve renal function better than large-volume paracentesis and possibly improve dyspnea and QOL. Some studies have shown improvement in abdominal distension, anorexia, and constipation.[94] A final catheter option is a double-cuffed pigtail peritoneal dialysis catheter (e.g., Tenckhoff), which allows for drainage of malignant ascites and the option to infuse cytotoxic medications, with an overall low complication rate.[95]

Shunts

TIPSS is typically reserved as a second-line option for patients with refractory ascites. This angiographic procedure involves creation of a low-resistance pathway from the hepatic vein to an intrahepatic branch of the portal vein, allowing for more balanced distribution of fluid volume. For cirrhotic patients, TIPSS offers better control of ascites than large-volume paracentesis and can improve QOL but unfortunately yields a higher risk of severe hepatic encephalopathy and so is best for those with lower risk of encephalopathy.[84] Many contraindications to this procedure exist, including significant heart failure, pulmonary hypertension, systemic infection, and biliary obstruction.

Another type of shunt is the peritoneovenous (e.g., Denver or Le Veen) shunt. In this situation, ascitic fluid is shunted from the intraperitoneal space into the superior vena cava via a pressure gradient.[90] This is sometimes utilized in patients unable to benefit from TIPSS or large-volume paracentesis and has 70% rate of symptom palliation.[90] There is also evidence of utility in symptomatic patients with refractory chylous ascites.[96] However, there is a lack of survival advantage and a high 25–40% complication rate, including pulmonary edema, shunt occlusion, pulmonary embolism, infection, and disseminated intravascular coagulation.[85,86,90] It is typically not performed in patients with a prognosis of less than 1 month. Bilirubin levels of more than 6 mg/dL are a contraindication to this procedure as this is associated with a higher risk of intravascular coagulation.[90]

Liver Transplant

For patients with cirrhosis or low-volume hepatocellular carcinoma in otherwise good health, liver transplantation may be an option to improve both symptoms and prognosis. However, fewer than 10% of patients with end-stage liver disease are eligible for transplant, and even fewer will have the opportunity to receive transplant.[93] This is unfortunately only very rarely an option in the palliative population.

HIPEC

“Closed abdomen” hyperthermic intraperitoneal chemotherapy (HIPEC) is a newer procedure indicated for malignancy with ascites and peritoneal carcinomatosis.[97] It involves the removal of ascites through drainage tubes and washout of the peritoneal cavity with isothermic saline, followed by intraperitoneal infusion of chemotherapy (often carboplatin or paclitaxel for ovarian and cervical cancer, or cisplatin or mitomycin for GI cancers), instilled at approximately 41°C. Ovarian cancer tends to be more susceptible to this approach than GI cancers.[97] HIPEC is generally well tolerated with less toxicity than systemic chemotherapy, but it does require hospitalization. Small studies have shown that it results in longer intervals between required paracenteses, decreased abdominal circumference, and improved QOL.[97] HIPEC is typically most successful when performed after surgical removal of all visible tumor (“optimal debulking”). Limitations of HIPEC include high expense, requirement of technical expertise not present at many institutions, and limited penetration of chemotherapy into the tumor.[90]

CART

Concentrated ascites reinfusion therapy (CART) is another newer treatment for ascites. The process involves paracentesis, followed by filtration of ascitic fluid to remove any malignant cells, bacteria, and excess fluid or electrolytes, after which the filtered, concentrated ascites is reinfused.[98] CART is indicated for patients with resistance to or who have adverse effects from diuretics. In patients with ascites from multiple causes, it has resulted in significant improvement in performance status, dietary intake, urine volume, body weight, and abdominal circumference.[98] Fever is a common adverse effect, and additional prospective studies utilizing this technique are warranted.

Case Study 4 (continued)

Mr. N undergoes ultrasound, which confirms ascites. He receives diagnostic paracentesis, which is not suggestive of infection, and workup is consistent with portal hypertension. He is started on spironolactone without significant improvement, but later receives therapeutic paracentesis with 5 L of straw-colored fluid removed, which greatly improves his discomfort for about 2 weeks. He is scheduled in clinic for recurrent paracentesis every 2 weeks and is taught positioning techniques, which aid in maintaining his QOL.

Bowel Management Summary

- Constipation is a common symptom in the palliative population and requires a proactive approach involving patient education, lifestyle changes, and, at times, pharmacologic intervention, often with stimulant or osmotic laxatives.
- Malignant bowel obstruction is associated with poor prognosis, and should prompt discussion about goals of care, as well as aggressive symptom management through procedural or pharmacologic approaches.
- Diarrhea negatively impacts QOL in the palliative population, and patients should be educated to involve their medical team in treating symptoms.
- The presence of ascites frequently portends a poor prognosis, and patients often benefit from drainage of the fluid and discussion about goals and values.

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CHAPTER 15

Medically Administered Nutrition and Hydration

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Key Points

- For many people, food and drink are synonymous with care, but medically assisted nutrition and hydration should be considered a medical intervention rather than a basic form of comfort.
- Decreased appetite or inability to tolerate or enjoy food and fluids is a natural sign of advanced disease and can be a source of distress for patients, family, and caregivers.
- Discussions and decisions regarding initiating or withholding medically administered nutrition and hydration at the end of life are guided by goals of care, evaluation of benefits and burden, ethical and cultural considerations, and the beliefs and wishes of the patient and family. These wishes should be documented in an advance directive.
- It is medically and legally acceptable for patients or families to choose to voluntarily refuse any form of nutrition or hydration.
- Nurses caring for patients and families faced with the decision to start or withhold or withdraw medically administered nutrition and hydration (MAHN) are responsible for promoting patient autonomy, providing education regarding benefits and burdens of interventions, promoting informed decision-making based on values, and delivering quality care with the rest of the care team.
- It is not recommended to provide MAHN at the end of life, particularly for those with end-stage cancer.

Case Study: A Patient with Chronic Obstructive Pulmonary Disease

Mrs. M is a 68-year-old woman with end-stage chronic obstructive pulmonary disease (COPD) and progressive functional decline who lives at home with her husband of 50 years. In the past 3 months, she was admitted to the hospital twice for pneumonia, with one admission requiring mechanical ventilation. Her primary care physician has been worried about her continued weight loss, and, despite his efforts with steroids and appetite stimulants, she has continued to lose weight and no longer has the energy to eat. She weighs 80 pounds and has lost 45 pounds in the past 6 months. A home-based palliative nurse visited her in her home, and, during the visit, Mrs. M's husband brings up the fact she only drinks her protein shake twice a day and is no longer eating anything else. He was worried about her "starving" and asked that she consider a feeding tube to "help her get her strength back." Mrs. M had the capacity to make her own decisions. The nurse proceeded with a conversation about goals of care regarding medically administered hydration and nutrition.

Introduction

In the context of providing palliative care, decisions to initiate or withhold and withdraw the interventions of medically administered nutrition and hydration (MAHN) can be challenging for the patient, the family, and members of the healthcare team. For patients in palliative care who are in the last days to weeks of life there is little evidence that nutrition or hydration offers any benefit at this stage of illness. In many cultures, providing food and fluids is synonymous with caring, hope, and comfort.[1] Decreased appetite or inability to tolerate or enjoy food and fluids is often a hallmark of the terminal phase of an illness. Individuals and their families may ask for MAHN to address a variety of situations (e.g., fears of starvation, weight loss, and dehydration). Clinicians may recommend medically administered nutrition (MAN) or hydration in specific circumstances (e.g., malnutrition, dehydration, new onset of delirium). As with any palliative care intervention, the nurse needs to understand the patient's illness trajectory and patient and family goals of care, which can be influenced by a person's culture or religion. The nurse also needs to be familiar with the current evidence for MAHN for patients with advanced illness as nurses often participate in conversations regarding treatment options and have a critical role in supporting the patient in identifying interventions that best meet his or her goals.

Natural Fluid Deficits in Advanced Disease

Homeostasis of fluids is achieved in normal individuals by matching daily water intake and fluid loss. This match ultimately provides maintenance and balance for stable composition of body fluids. About 2,500 mL is the average amount of water consumed and lost per day. Fluid can be lost through kidneys, the gastrointestinal (GI) tract, lungs, and skin. Fluid deficits in terminal patients can have varying etiologies and be multifactorial. Regardless of the cause, the result is a naturally occurring fluid deficit disorder with both hypovolemia and dehydration.

As patients enter the dying process, it is most often characterized by diminished oral intake, progressive fluid deficits, and progressive accumulation of drugs, which can cause new symptoms or exacerbate existing ones (e.g., fatigue, dizziness, myoclonus, sedation, and hallucinations).[2,3] This phenomenon results in a further decline in the ability to drink fluids. During this phase, the evidence suggests diminished awareness, which may decrease the patient's perception of thirst and hunger.[4–6]

Medically Administered Nutrition

MAN is the provision of nutrition that involves non-oral enteral or parenteral delivery of nutrients. Enteral approaches include nasogastric (NG), percutaneous endoscopic gastrostomy (PEG), percutaneous endoscopic gastrostomy jejunostomy (PEG-J), or gastrojejunostomy (G-J) tubes.[2] Parenteral approaches include central or peripheral venous access.

MAHN is a medical intervention to address malnutrition, which has been linked to poorer outcomes such as increased mortality, infections, and pressure ulcers.[3] Malnutrition occurs when the body does not get the nutrients it needs.[7] Causes of malnutrition include an inadequate diet, mechanical issues with digestion or absorption of nutrients, and specific medical conditions.[8] In patients with advanced chronic disease or terminal illness, specific causes for malnutrition may result from anorexia, cachexia, and physiological issues. When caring for multimorbid patients with advanced disease there are often a myriad of etiologies for malnutrition and fluid electrolyte imbalances. The hospice and palliative nurse plays an integral role around assessment, treatment, support, and ongoing evaluation for patients contemplating MAHN. Anorexia manifests with a decrease in appetite, which can lead to a loss of fat tissue. The weight loss that results can be reversible depending on the underlying causes. Many patients with advanced illness experience anorexia.[4] Cancer cachexia is a multifactorial syndrome in which there is loss of skeletal muscle that cannot be completely reversed by nutritional support, resulting in a negative impact on functional status.[8] Mechanical issues include malignant bowel obstruction and dysphagia.

Benefits and Burdens

While the benefits of MAN are clearer in patients who are expected to recover, they are not as clear in patients who have advanced chronic illness or who are terminally ill.[9] The expected benefits include improving a patient's nutritional status to alleviate distressing symptoms resulting from malnutrition; however, MAN in the palliative care setting does not always have a positive impact. In amyotrophic lateral sclerosis (ALS), there are guidelines recommending the use and timing of MAN since malnutrition and weight loss are prognosticators for survival.[10–12] In patients with cancers of the oropharynx or esophagus, MAN may be appropriate earlier in the disease trajectory, especially when the cause of malnutrition is directly related to the inability to maintain intake due to mechanical blockages and acute treatment effects (e.g., mucositis secondary to chemoradiation).[13] For patients in a permanent vegetative state (PVS), life expectancy can be extended by months to years.[14] Outside of these clinical diagnosis and settings, studies indicated that MAN has no effect on prolonging life or improving functional status in advanced illness.[15]

Table 15.1 Potential complications of enteral support

Complication	Symptom	Cause
Aspiration	Coughing	Excess residual
	Fever	Large-bore tube
Diarrhea	Watery stool	Hyperosmotic solution
		Rapid infusion
		Lactose intolerance
Constipation	Hard, infrequent stools	Inadequate fluid
		Inadequate fiber
Dumping syndrome	Dizziness	High volume
		Hyperosmotic fluids

A study looking at whether clinical, functional, or nutritional indices could determine if patients would benefit from MAN found that comorbidity, cognitive function, and social function could predict a patient's success with MAN.[16] This same study found that predictors of the ineffectiveness of MAN on clinical outcomes included severe cognitive impairment and frailty.

While there may be some benefit in certain populations with end-stage diseases, enteral and parenteral feedings are interventions with the potential for associated morbidity and increased suffering. Patients and families worry about anorexia and believe MAN to be beneficial to address both physical and psychosocial symptoms.[17,18] Therefore it is critical for the nurse caring for these patients and families to not only review the benefits and burdens medically, but also to explain the long-term caregiving, financial, social, and emotional impact of long-term MAN.

Potential complications from the administration of MAN are listed in Table 15.1. Potential additional burdens include complications from tube placement, increased risk of infection or skin excoriation around the tube, and use of mechanical or pharmacologic restraints to preserve access.[19]

Malnutrition, Anorexia, and Cachexia

In many end-stage diseases, weight loss due to malnutrition, anorexia, or cachexia is a common occurrence. In cancer patients with persistent anorexia and cachexia, MAN has not been shown to reverse the weight loss.[20] It is commonly thought that weight loss may be secondary to the release of cytokines that increase protein degradation.[21] In one study looking at body mass index (BMI) as a specific marker of nutritional status, the provision of MAN helped to stabilize decreases in BMI for patients who were alive at the 3-month follow-up (10 out of 17 patients); however, the study did not measure quality of life (QOL) for the same population. [22] In the terminal phase of diseases such as cancer, MAN may not be metabolized in a way that would reverse the effects, and the intervention for palliative purposes is rarely recommended.[23,24]

Dysphagia

When a patient has difficulty swallowing, MAN may be considered to ensure that the patient receives adequate nutrition or to reduce the risk for aspiration pneumonia. In certain disease states, such as ALS and dementia, it is a matter of when, not if, dysphagia will occur. For ALS patients, the goal for enteral feeding is to improve the QOL and the preferred mechanism to deliver MAN, if indicated, is via a PEG tube.[25] The onset of dysphagia and the resulting weight loss are indications of when to start MAN in the ALS patient population.[12] Providers may consider initiating enteral feeds to reduce the risk for aspiration pneumonia due to "food going down the wrong way"; however, recent studies have shown that enteral nutrition does not reduce, and may increase, the risk for aspiration pneumonia.[20,26,27]

Hunger

Families often express concern about their loved one experiencing hunger or have fears about their loved one starving at end of life, yet patients will often deny sensations of hunger in the terminal phase. A study looking at the incidence of hunger in a terminally ill population found that most patients (63%) denied hunger on admission and did not report any hunger during the admission. Of the remaining patients, only 3% (one patient) reported hunger throughout the admission; the others complained initially, but the hunger disappeared over time. These patients were offered food by mouth as requested, and the small amounts they tolerated satisfied their hunger; none was given MAN.[4] In advanced cancer and dementia, hunger is not a symptom often experienced due to the natural disease process.

Pressure Ulcers

Patients who are malnourished are at increased risk for pressure ulcers, yet, at the end of life, there is no evidence to support the use of MAN to treat or prevent pressure ulcers.[20,26] One study showed that in patients with dementia, the use of a PEG tube to administer MAN was associated with an increased risk of developing new stage 2 pressure ulcers and a decreased likelihood of the healing of existing pressure ulcers.[29] Potential reasons for this association include risk factors such as increased likelihood of immobility due to the use of restraints that may be used to ensure that feeding tubes are maintained and potential for diarrhea due to the composition of the enteral feeds.[29]

Survival Time

There is no compelling evidence that MAN increases the survival of patients with end-stage diseases.[20,26] For patients with advanced dementia, studies do not indicate that MAN prolongs life.[27] The literature suggests that there is also no indication of improved overall function, prevention of aspiration, or reduced pressure sores.[30,31] One study found a median survival post–feeding tube insertion of 165 days and a 64% mortality rate, with half of those who died doing so within the first 2 months following insertion.[32] Another study compared the impact on survival time of PEG tube insertion or the timing of the insertion and found no impact.[33] Other studies have shown an increase in survival in specific populations. One study compared survival time in dementia patients in Japan who used self-feeding oral intake versus home parenteral nutrition or PEG feeding and found that the groups who used either home parenteral nutrition or PEG feeding survived almost twice as long.[33] In this study, patients were not in the end-stage of dementia, which may explain the longer survival time. Another study looked at whether dementia was a risk factor for survival after PEG and found no difference in survival between patients with dementia and patients without who received a PEG tube.[34] The authors did not include the stage of dementia in their analysis.

Quality of Life

There have not been many studies that specifically measure QOL for patients with end-stage illness receiving MAN. In a Cochrane review of enteral tube feeding in an older population with advanced dementia, there were no studies reviewed that measured QOL. Another Cochrane review found two studies that did not demonstrate improved QOL in both a population with motor neuron disease or with advanced cancer.[35] Patients and their families determine the impact of interventions such as MAN on QOL. Some studies have shown that patients and families perceive MAN to have a positive impact on reducing burden from physical and psychosocial symptoms, such as maintaining the fight against the disease, reducing anxiety due to anorexia, and alleviating symptoms. Other studies have looked at the use of MAN and the prevalence of interventions that may be thought to negatively impact QOL, such as the use of restraints. In studies looking at patients with dementia receiving tube feeds, MAN has been correlated with an increased use of restraints, either physical or pharmacological.[28,36] In a study assessing family members' perceptions of the impact of a feeding tube, only 32.9% of the people who responded stated that the intervention improved the patient's QOL.[37]

Summary

MAN has been shown to have a positive impact on survival and nutritional parameters in certain populations, such as earlier in the disease trajectories for ALS or some cancers. However, there is not enough evidence to support a specific recommendation on when or if, in a palliative care population, it is best to use MAN.[28] The individual patient's condition, along with the goals of care, needs to be considered to best determine the benefit of employing MAN compared to the burdens of the intervention.

Hydration

Medically administered hydration is the provision of water or electrolyte solutions by any route other than the mouth. This can be achieved by intravenous, subcutaneous (hypodermoclysis), and rectal (proctoclysis) administration.[37]

Hydration is an intervention used to address situations such as fluid deficits and altered mental status secondary to medication toxicities in advanced disease. Fluid deficit disorders include dehydration and volume depletion. *Dehydration* is intracellular water depletion with hypernatremia (hyperosmolality) and usually presents with symptoms of thirst, anorexia, nausea/vomiting, fatigue, and irritability. Physical findings may include lethargy, confusion, muscle twitching, and hyperreflexia. *Volume depletion* is the loss of intravascular water (with varying sodium levels) and presents with diminished skin turgor/capillary refill and orthostatic hypotension and dizziness.[29] Patients with advanced illness experiencing anorexia may also experience a loss of interest in drinking.[38] During the terminal phase, fluid deficits, similar to malnutrition, may result from anorexia/early satiety, nausea/vomiting, bowel obstruction, dysphagia, and cognitive impairment.[29,39,40]

Some patients and families believe that decreased oral intake and the ensuing dehydration causes suffering. Patients and families are concerned that dehydration may precipitate symptoms of delirium, confusion, myoclonus, somnolence, fatigue, neuromuscular irritability, restlessness, thirst, hunger, and constipation, especially in the presence of opioids, benzodiazepines, and neuroleptics.[41] There is limited information regarding the effects of hydration in addressing these symptoms. Many patients with advanced cancer and their caregivers perceive that hydration provides hope and comfort, improves symptoms and QOL, and fulfills a basic human need for water. Emphasis on the importance of taking the patient's specific diagnosis, wishes, and hopes into consideration when discussions about medically administered hydration arise is imperative.[42]

When considering hydration, it is important to consider where the patient is on the disease trajectory (e.g., acutely ill or in the dying phase) to help establish goals of care. Hydration can be used for the temporary relief of symptoms of fluid loss such as nausea, vomiting, diarrhea, and fevers; to decrease fatigue; to improve mental cognition status associated with medication toxicities; and as a respect to cultural and familial beliefs.

Methods of Administration

There are various alternative routes to oral administration to meet the goals of care and wishes of the patient and family. Standard methods for replacement of fluids, similar to nutrition, can be achieved by the use of enteral feeding tubes and parenteral methods, such as subcutaneous or intravenous infusion.

Intravenous access requires a competent vein. Clinicians may use permanent access devices if they have previously been placed or if ongoing hydration is anticipated. *Hypodermoclysis* is the subcutaneous infusion of isotonic solution. It does not require special access devices and can be used for patients who have poor venous access for intravenous placement. The absorption of the subcutaneous fluids has been found to be comparable with absorption of intravenous fluids when administered appropriately.[37,39] *Proctoclysis* is used to administer water or saline into the GI tract via the rectum using a nasogastric tube. Researchers have found proctoclysis to be safe and economical, but there has been cultural and social reluctance to accept this mode of administration.[41]

There is no consensus regarding the volume or type of fluid replacement. Clinicians make choices based on previous experiences and knowledge of the patient's condition and wishes. Some providers allow the individual to have 1 L/day even though it may be inadequate replacement. Risks and burdens must be considered (Table 15.2).

Table 15.2 Potential complications of routes for medically administered hydration

IV Peripheral	IV Central	SC Hypodermoclysis
Pain	Sepsis	Pain
Short duration of access	Hemothorax	Infection
Infection	Pneumothorax	Third-spacing
Phlebitis	Central vein thrombosis	Tissue sloughing
	Catheter fragment thrombosis	Local bleeding
	Air embolus	
	Brachial plexus injury	
	Arterial laceration	

IV, intravenous; SC, subcutaneous.

Benefits and Burdens

The decision for hydration needs to include an evaluation of goals of care, discussion of the risks and benefits, and timely reevaluation to determine if goals or symptoms are improving or worsening. Insurance coverage, impact on healthcare benefits, social impact, and maintenance of administration should be carefully evaluated and requires input from the other healthcare team members. Risks for overhydration, as evidenced by worsening fluid retention, signs of increased shortness of breath, increased emotional distress, or change in mental status, must be monitored. Advantages of not providing medically administered hydration can include reduced urine output, leading to reduced incontinence and need for catheterization; reduction of GI secretions, leading to decreased incidence of vomiting; and decreased respiratory tract secretions, leading to decreased cough and need for suction.[41]

Factors arguing against initiating hydration include increasing the incidence of pulmonary and peripheral edema and increased respiratory tract secretions, cough, and ascites.[41–43] Starting intravenous hydration can cause pain, be distressing, restrict mobility, hinder family contact, and increase the use of restraints.[44]

Review of the Literature

Dehydration and Fluid Retention

Dehydration can cause unpleasant symptoms such as confusion and restlessness in non–terminally ill patients.[45] These problems are common in the dying. There is limited research regarding the effect of hydration on alleviating dehydration at the end of life. Results can be challenging to interpret due to the ways various studies define and measure dehydration. Findings suggest that providing medically administered hydration may or may not affect physical signs and symptoms of dehydration at the end of life. One study demonstrated no difference in hydration status after 7 days between advanced cancer patients who were given 1,000 mL/day versus 100 mL/day. The same study also scored four dehydration symptoms (fatigue, myoclonus, sedation, and hallucinations) and noted no difference in the sum of the scores after the 7-day hydration trial.[46] A retrospective chart review study showed that medically administered hydration in the last 48 hours of life had no significant impact on symptoms related to hydration status (e.g., agitation, myoclonus, urinary retention, confusion, congestive cardiac failure, respiratory tract secretions, nausea and vomiting, and ascites).[41] These findings suggest that there is no benefit of hydration during the terminal phase.

Depending on the volume of hydration administered, hydration may increase the risk of developing fluid retention symptoms. In a study that measured the effect of hydration volume on terminally ill cancer patients with abdominal malignancies, dehydration was evaluated based on physical findings that included moisture on the mucous membranes of the mouth, axillary moisture, and sunken eyes within 72 hours of death. Patients in the hydration group who received 1,000 mL or more of medically administered hydration per day 1 and 3 weeks before death were found to have less deterioration in dehydration symptoms than the nonhydration group who received on average less than 1,000 mL of medically administered hydration over the 3 weeks prior to death. However, the patients who were in the hydration group were noted to have increased symptoms of overhydration such as edema, ascites, and bronchial secretions. No difference was noted between the groups regarding pleural effusion.[46] These findings are similar to a study that showed increased dehydration status in the nonhydration group who did not receive hydration and increased fluid retention symptoms of peripheral edema and ascites in the hydration group.[44] A prevalence of bronchial secretions in the last 48 hours of life was noted more in the large-volume group that received more than 1,000 mL hydration per day compared to those in the small-volume group that received less than 1,000 mL/day.[47]

A national guideline for parenteral hydration therapy was established in Japan in 2007 that encouraged respecting patient and family wishes, conducting a comprehensive assessment of patient's QOL, allowing for total parenteral nutrition to be administered if bowel obstruction was present, and recommending that hydration be decreased to less than 1,000 mL/day if fluid retention signs were present.[48] A study to measure the efficacy of this guideline demonstrated that providing hydration to patients with advanced cancer according to the guidelines led to stable measurements in global QOL, discomfort, most physical symptoms, and fluid retention signs.[49]

Thirst and Dry Mouth

Thirst is thought to be a nonspecific symptom of dehydration. One study looked at interventions for thirst and dry mouth as an alternative to hydration. Researchers found that routine care, defined as offering food and fluids, administering ice chips, and providing mouth care, helped to alleviate these symptoms.[4,47] Dry mouth is treated with an intensive, every 2-hour schedule of mouth care, including hygiene, lip lubrication, and ice chips or popsicles. Elimination of medications that cause dry mouth, such as tricyclic antidepressants and antihistamines, should be considered. Sometimes, drugs that contribute to these symptoms are being administered to palliate other symptoms, such as the opioids for pain and anticholinergics to minimize oral secretions. Mouth breathing can also contribute to dry mouth. *Candida* infection, a frequent cause of dry mouth, can be treated. Agents such as pilocarpine can be used to increase salivation.

In one study, hydration was shown to alleviate symptoms of dry mouth in patients with advanced cancer who have a relatively longer prognosis. It was noted that dry mouth intensity decreased significantly in the group receiving a large volume of hydration (1,000 mL/day or more) than those in the small-volume group (less than 1,000 mL/day). This same group also experienced a higher incidence of bronchial secretions.[49]

Delirium, Confusion, Agitation

Delirium can be caused by multiple factors including end-organ failure, dehydration, and medications. Symptoms of delirium can be distressing for patients and families. In advanced cancer patients, no significant difference in delirium and agitation was noted between patients receiving more hydration than less hydration.[46,48]

Medications such as opioids, anticholinergics, antihistamines, and corticosteroids have been known to impact delirium. If delirium is related to the accumulation of opioids, interventions to decrease or rotate opioids and to increase hydration are believed to control the symptoms of hyperactive delirium, such as agitation and hallucinations of opioid-induced neurotoxicity, by assisting with the clearance of toxic opioid metabolites.[49]

Myoclonus

Myoclonus, or involuntary contractions of muscles, is commonly associated with chronic opioid use at the end of life. It has also been reported in cancer patients without opioid use who are experiencing decreased oral intake.[39] There is limited and mixed information regarding the effects of hydration on myoclonus depending on patient setting. Myoclonus was shown to improve in the intervention group who received 1,000 mL normal saline over 4 hours for 2 days versus 100 mL.[51] However, no difference in myoclonus symptoms was noted between patients with advanced abdominal malignancies in the hydration group who were given on average 838 to 1,405 mL/day during the last 3 weeks of life and in the nonhydration group who received an average of 200 mL/day.

Survival Benefit

There is limited research regarding the survival benefit of hydration. Two studies noted that hydration provided no survival benefit for terminally ill cancer patients with short prognosis.[46,48]

Quality of Life

There is limited research regarding the impact of hydration on QOL in the terminally ill. Research on patients with advanced cancer shows that parenteral hydration of 1,000 mL/day did not improve symptoms associated with QOL over placebo of 100 mL/day.[50] Another study showed that QOL measurements remained stable when hydration was administered according to Japanese guidelines that took into account QOL and symptoms of fluid retention whether patients received small (<1,000 mL/day) or large (>1,000 mL/day) volumes of hydration.[49] In a study that interviewed patients with advanced cancer and their caregivers, both patients and their caregivers perceived hydration as fulfilling the basic human need for water, promoting hope and dignity, and enhancing QOL. Caregivers in the same study reported that hydration improved pain management and that the patient had more energy, better sleeping habits, an improved appetite, and a healthier physical experience. The study did not include information on volumes or duration of hydration.

Summary

Parenteral hydration has been found to be effective in temporary, short-term situations to alleviate symptoms related to dehydration and improve mental cognition. In the palliative care setting, research does not support that parenteral hydration improves signs of dehydration, survival, or QOL. In the setting of delirium related to opioid toxicity, there is mixed evidence supporting hydration and possible opioid rotation to improve delirium symptoms. When deciding to initiate or stop hydration, it is important to assess goals of care, risks and benefits, and the patient's preferences related to his or her values and needs.

Case Study: A Patient on Dialysis

Mr. D is a 54-year-old man with dialysis-dependent renal disease. He was sent to the emergency room from his dialysis center secondary to lethargy and confusion. He lives independently at home and has no advance directives. After an evaluation, he was found to be dehydrated and was given a slow infusion under observation at the hospital. Once he returned to baseline, he was sent home. One month later, Mr. D had decompensated with functional and nutritional decline. His primary care provider referred him to the community-based palliative team. He was visited by his palliative nurse practitioner at home, and Mr. D explained that he no longer wanted to go back to the hospital for any form of treatment. His daughter was worried that, if he became dehydrated again, she would be unable to get him fluids and insisted that he go if he needed them.

Review of Position Statements and Guidelines

Many professional organizations have published position statements or guidelines on the use of MAHN. Common themes across these documents include:

- MAHN is an intervention that should be evaluated by the patient, family, and care team with careful consideration of its benefits and burdens.[52,53]
- MAHN is considered a medical intervention that can be refused, withheld, or withdrawn based on the patient's clinical condition and goals of care.[28,54]
- Decisions about MAHN need to reflect the patient's and family's values, beliefs, and culture.[54]

In addition to general position statements regarding MAHN, disease-specific recommendations are summarized in Table 15.3.

Decision-Making and MAHN

Decisions about the initiation or withholding and withdrawing of MAHN are complex.[54] In addition to the review of the clinical evidence regarding the efficacy of MAHN to improve symptoms and QOL, it is important to consider ethical principles and legal precedents that highlight the role nurses have in advocating for the patient as well as their responsibilities in respecting patient and family wishes. While the withdrawing of medically administered nutrition and/or hydration may cause more emotional distress for clinicians as well as for patients and their families than withholding such treatment, there is no ethical or legal distinction between them.[2] When decision-making is difficult or complicated by a particular goal or value, a short goal-based trial can be offered with the intention of temporary support being emphasized. In this circumstance, the patient should be routinely assessed for adverse effects of the MAHN intervention (Table 15.4).

Ethical Issues

Initiating or withholding or withdrawing MAHN, like other medical interventions, needs to be done utilizing ethical principles. The three ethical principles that are most relevant in decision-making for MAHN are autonomy, beneficence, and nonmaleficence.[55] Autonomy refers to the patient's or surrogate's right to self-determination. Respecting autonomy in decisions about MAHN means that a patient or family has the choice to accept or refuse the intervention based on their personal values and beliefs.[55] Beneficence means "to do good" and implies that nurses must act in the interest of the patient.[55] The nurse has a responsibility to engage the patient and family in a conversation about what "good" looks like, respecting the individual's values and goals for care. For example, a patient with end-stage cancer may be experiencing dysphagia yet still finds enjoyment in small sips of liquid. While the risk for aspiration exists in this situation, the nurse would exhibit beneficence by supporting the intake of fluids. Nonmaleficence means "to do no harm" and can be exemplified by not administering treatments that increase the risk of suffering and have no benefit or whose benefit is less than their burden (Table 15.5).[55]

Table 15.3 Disease specific guidelines for medically administered nutrition and hydration (MAHN)

Advanced Dementia[21]	◆ Feeding tubes are not recommended. ◆ Enhance oral feedings by improving the environment and supporting patient-centered approaches.
End-stage Cancer[18,19]	◆ Use of nutritional support for terminally ill cancer patients is not usually indicated.
ALS[20]	◆ Early insertion of a feeding tube is recommended if enteral feeding is determined to be an appropriate intervention.

Legal Precedent

Landmark cases such as the Quinlan case, Cruzan case, Barber case, and *Vacco v. Quill* have set the foundation for current decision-making regarding MAHN within the healthcare system. Karen Ann Quinlan was 21 years old when she was deemed to be in a persistent vegetative state due to anoxic brain injury. Her father sought guardianship to cease "extraordinary" measures keeping her alive.[56] In this case, the court supported the standard of substituted judgment, enabling her father to speak for her as if she could speak for herself.[57] Nancy Cruzan was thrown from her vehicle in a car accident. Although found by the paramedics with no pulse, they were able to resuscitate her. She was in a coma for several weeks before being determined by her physicians to be in a persistent vegetative state.[58] In her case, the court supported the right to refuse treatment for competent individuals. The court also supported the need for "clear and convincing evidence" since she was incompetent and had not previously recorded her wishes. This case helped to support the federal Patient Self-Determination Act passed in 1991 in an effort to help patients document their wishes.[59] The *Vacco v. Quill* case also supported the right to refuse treatment, distinguishing respecting patient wishes from intentionally hastening death.[59] In the Barber case, the court found two physicians who had discontinued MAHN to be innocent from charges of murder and conspiracy to commit murder, reinforcing the precept that MAHN is considered a medical intervention and not basic care.[59]

Religious and Cultural Issues

To deliver patient-centered care, nurses must recognize the role that religious or spiritual beliefs and culture, including race and ethnicity, play on patient and family values surrounding food and fluids. Understanding these factors and encouraging a dialog about patient values will enable nurses to respect patient autonomy and engage in a dialog of how to meet patient needs regarding nutrition and hydration to maximize beneficence ("to do good") and minimize nonmaleficence ("to do no harm"). Integrating other care team members with experience in this area can be extremely helpful to all stakeholders. In particular, social work and chaplain support will assure that patient and family psychosocial and spiritual needs are met.

In reviewing the common beliefs of various religious traditions and cultures, it is important to remember that not everyone of a particular faith or a particular culture will have the same beliefs,

Table 15.4 Hydration and/or nutrition in advanced illness or end of life: Key studies

Author, Year, Design	Sample Size and Characteristics	Variables Evaluated	Results	Overall Impact of Hydration
Nakajima, Hata, Kusumuto, 2013 Observational Study	75 terminally ill patients with GI malignancy	Hydration score	Dehydration score was higher in nonhydration group (35% vs. 13%, p. 03); edema/ascites/bronchial secretions higher in hydration group (57% vs. 33%, p. 04)	No benefit secondary to adverse effects
Bruera, Hui, Dalal, et. al, 2013 Randomized Controlled Trial	129 patients in hospice care	Symptoms for dehydration, delirium, myoclonus, and survival	No difference between treatment and control groups in delirium, dehydration	Negative
Morita, Hyodo, Yoshimi, et al, 2005 Prospective Controlled Trial	226 advanced cancer patients (59 hydrated and 167 non-hydrated)	Dehydration and fluid retention symptoms	No significant difference in dehydration or retention symptoms	Negative
Bruera, Sala, Rico, et al, 2005 Randomized Controlled Trial	60 dehydrated patients with advanced cancer	Symptoms of dehydration	Mixed for sedation and myoclonus improvement, composite score for fatigue, hallucinations	Mixed
Morita, Tei, Tusnoda, et al, 2001 Observational Study	88 terminally ill cancer patients in hospice	Assessment using visual analogue scale (VAS) on symptoms of thirst	No correlation of thirst scores	Negative
Cerchietti, Navigante, Sauri, Palazzo, 2000 Randomized Controlled Trial	42 advanced cancer patients who were dehydrated	Thirst, nausea, delirium and mini-mental status exam (MMSE), anguish, mood	No significant differences in groups	Negative
Ellershaw, Sutcliffe, Saunders, 1995 Observational Study	82 cancer patients two days before death	Thirst, respiratory secretions, dry mouth	No correlation between hydration status and thirst	Negative
Musgrave, Bartal, Opstad, 1995 Uncontrolled Trial	30 cancer patients in the last day of life	Thirst level	All patients who were alert experienced some level of thirst.	Negative
McCann, Hall, Groth-Juncker, 1994 Uncontrolled Trial	32 terminally ill patients who were mentally aware	Thirst, hunger, and dry mouth	63% no hunger, 34% initial hunger only, 62% no thirst or initial thirst	Negative
Waller, Hershkowitz, Adunsky, 1994 Observational Study	68 cancer patients within 48 hours of death, 13 received fluids	Consciousness	No correlation in improvement of consciousness and administration of fluids	Negative

and nurses should inquire as to how much influence a patient's faith or culture has on his or her beliefs regarding MAHN. Clinicians should be aware that some religions may view voluntary cessation of hydration and nutrition as an intentional and forbidden shortening of life. Even within religions, there can be varying opinions or interpretations of religious law to guide decisions on whether to initiate or withdraw MAHN. Table 15.6 summarizes beliefs by selected religious traditions specific to MAHN.

In addition to religious influences, culture also affects patient and family perspectives on MAHN. Studies have shown variance associated with race in the use of tube feedings, with Caucasians having lower rates than people of other cultural backgrounds.[60] In studies

Table 15.5 Medically administered nutrition and hydration (MAHN): Examples of nursing interventions that reflect ethical principles

Ethical Principle	Nursing Actions
Autonomy: Respecting an individual's right to make choices regarding care	Encourage a conversation that provides information on the benefits and burdens of MAHN to empower the patient to make an informed decision. Focus on patient's preferences, especially when working with family and caregivers. Ask, "Did we do everything to meet the patient's goals?" not "Did we do everything possible?"
Beneficence: "To do good"	Seek to understand the patient's goals and values to understand what "good" means for them. Provide interventions that match with patient goals.
Nonmaleficence: "To do no harm"	Evaluate the potential risks or burdens of MAHN to minimize harm, taking into account the patient's values.

Table 15.6 Various religious beliefs about medically administered nutrition and hydration (MAHN)

Religious Faith	Beliefs
Buddhism[1]	◆ Belief that all beings suffer. ◆ Main focus at end of life is on spiritual comfort. ◆ Less focus on extending life through MAHN and other interventions.
Catholicism[2,3]	◆ Current position (as of 2011) focuses on "life prolongation based on fundamental human dignity." ◆ Some within the church assert that MAHN is not considered a medical technology, but an ordinary measure to preserve life. ◆ Others feel that MAHN should be evaluated using the proportionate/disproportionate framework (ordinary vs. extraordinary) on an individual basis. ◆ Catholic healthcare facilities are obligated to offer food and fluids regardless of disease state. ◆ MAHN can be considered extraordinary in conditions where the underlying disease would be the cause of death, not the withholding of MAHN.
Hinduism[1]	◆ Withholding or withdrawal of MAHN at the very end of life is acceptable. ◆ Some Hindus fast to prepare for death.
Islam[4]	◆ "Guiding purpose of Islamic law is to protect and preserve religion, life, progeny, intellect, and wealth." ◆ Islamic rules regarding care for terminally ill are based on the principle that one should prevent or avoid injury or harm. ◆ Islamic law permits withdrawal of MAHN and allowing the disease to take its natural course. ◆ There can be various beliefs among Muslims, so it is necessary to ascertain the patient's values. ◆ "Islamic law states that palliative care should not shorten a patient's life, but futile treatment is not justified." ◆ "Islamic law forbids passively or actively causing death." ◆ Nutritional support is considered basic care and not medical treatment, leading to a duty to feed patients who are no longer able to feed themselves. ◆ Varied opinion among different Islamic communities regarding withdrawing and withholding MAHN.
Judaism	◆ Provision of food and fluids are considered ordinary measures, not extraordinary. ◆ Withholding food and fluids is not consistent with Jewish law. ◆ Administration of food and fluids, even via IV or feeding tube, is not considered to be artificially administered. ◆ "The religious authorities hold that [MAHN is] ordinary supportive measures rather than heroic."[5] ◆ Terminal dehydration, hospice without provision of MAHN, and withdrawing or withholding MAHN is not considered aligned with Jewish teaching unless there is proof of *goses* (less than 72 hours until death) and futility of intervention under any denomination of Judaism. ◆ "While the [Israeli] law respects the right of a competent dying patient to refuse nutrition and hydration, it introduces a legal requirement to persuade 'the use of oxygen, nutrition and hydration,' even by artificial means."[6]
Protestantism	◆ There is diversity in positions regarding MAHN across denominations. ◆ Common belief that interventions such as MAHN that allow time for repentance may outweigh other burdens of treatment.

[1] Reference 60. Heuberger

[2] Bradley CT. Roman Catholic doctrine guiding end-of-life care: a summary of the recent discourse. *J Palliat Med*. 2009;12(4):373–377.

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[4] Alsolamy S. Islamic views on artificial nutrition and hydration in terminally ill patients. *Bioethics*. 2012. doi: 10.1111/j.1467-8519.2012.01996.x.

[5] Rosner F, Abramson N. Fluids and nutrition: perspectives from Jewish Law (Halachah). *South Med J*. 2009;102(3):248–250.

[6] Ravitsky V. A Jewish perspective on the refusal of life-sustaining therapies: culture as shaping bioethical discourse. *Am J Bioeth*. 2009;9(4):60–62.

looking at the use of feeding tubes between white subjects compared to African American subjects, use was consistently higher in the latter group.[61] Studies have also shown that African Americans have a stronger preference for more intensive care.[62] One study looked at preferences between African American and Caucasian participants using focus groups, assessing for factors that might affect decisions about care at end of life, including MAN. From the qualitative data gathered in the focus groups, the researchers found more similarities than differences in how the two groups thought about food, AN, and decision-making at end of life.[62] The differences were not by category, but more on focus within common themes.[62]

In a study looking at what meaning Singaporean Chinese caregivers attributed to feeding, the researchers found three major themes emerge. One theme was a sense of filial piety, where duty to one's family may motivate a push for more aggressive interventions even if the patient is at the end of life. Another theme was the link between providing nutrition and hope. A third theme was that providing food showed caring for their loved one, a theme common across many cultures.[63]

While there is not a large body of research on how differing religious and cultural backgrounds influence individual preferences for MAHN, there are resources that nurses can access to learn the information needed to initiate a conversation with a patient on this issue. Whether it is through position statements from religious organizations or talking to leaders within a religious, tradition, or ethnic community, nurses can seek to understand how these factors play a role in each specific situation with the patient for whom they are caring.

Engaging in Conversations and Goals of Care about MAHN

In working with palliative care and terminally ill patients, nurses play a pivotal role in exploring a patient's values and hopes to ensure that care related to the provision of food and fluids is person-centered. Because decisions about MAHN are complex, nurses have multiple responsibilities. Nurses need to self-reflect, understand the literature, understand the position statements, understand the prognosis, and thoroughly assess the patient and family unit as a whole prior to making a nursing plan or recommendations.

One of the primary tasks of the nurse is to ensure that a patient's autonomy and dignity is respected in a way that is culturally acceptable to the patient by understanding the patient's values regarding MAHN and the broader goals that the individual is hoping to achieve. This task can be accomplished by promoting early conversations regarding patient and family preferences. The focus should be on the patient as the decision-maker, even if the patient is not participating in the conversation. While open-ended questions may encourage exploration of knowledge and understanding of patient and family hopes, focused and directed questions regarding preferences may guide patients and families to more concrete goals and decisions. Two important questions to consider in the decision-making process regarding MAHN are (1) What are the views and preferences of the patient? and (2) What are the individualized goals of care? Having an evidence-based goals of care framework that addresses both short- and long-term goals and the feasibility of those goals can be helpful. A challenge in performing this task arises when patient and family preferences conflict with a nurse's or health care team's preferences for treatment. The focus of discussions should be "Did we do everything to meet the patient's goals?" not "Did we do everything possible?"

Additionally, nurses can empower patients and families by educating them about the normal symptoms of the dying process and the known benefits and burdens of MAHN as an intervention to effectively treat symptoms associated with dying. To facilitate informed decision-making, education can focus on symptoms and progression of the normal dying process, available options for MAHN, and known benefits and burdens of MAHN interventions, as well as the limitations of evidence supporting MAHN in managing some symptoms and alternative options to treat distressing symptoms. Patients and families should also be informed that MAHN can be withheld and withdrawn. If a nurse is unable to provide appropriate information, the nurse should feel comfortable with saying "I do not know" over providing false reassurances.[62] It is recommended that the nurse seek counsel from available resources such as the primary team, the interdisciplinary team, or the palliative care team and then return to the patient and family with information. By providing this care coordination, the channels of communication are opened between individuals caring for the patient and will allow for improved alignment as a team in supporting complex care decisions.

Initiating and Withdrawing or Withholding MAHN

If the decision is made to initiate MAHN in a patient to meet the goals of care, the nurse has a responsibility to continually assess the patient's condition, evaluating the impact of the intervention on symptoms and the patient's responses to treatment. MAHN can be offered as a time-limited trial to determine whether the patient experiences any benefits from the intervention compared to burdens. As MAHN is often instituted during an acute event while in the hospital, nurses can inquire about previous medical history or expressed wishes and promote conversations that look at the bigger picture beyond the acute admission.[64] Nurses in any setting can inform patients and families early in the disease continuum of the progression of the illness and ensure that wishes are elicited and documented by the healthcare team regarding MAHN. The nurse needs to facilitate ongoing conversations about MAHN to ensure that the role of this therapy continues to meet patient and family goals without excessive burden.

If the decision is made to either withdraw or withhold MAHN, the nurse can provide emotional support and assurances that the patient's dignity will be respected with comfort care. If the patient is able, it is OK to gently encourage oral intake if it is compatible with the patient's overall goals. If eating and drinking becomes too difficult or requires too much effort, the patient should not be pressured. Alleviation of symptoms of dry mouth and thirst should be a focus and can include gentle oral cleaning, ice chips or popsicles, moistened sponges, lip moisturizer, and artificial saliva.[50,65] If unable to support a patient or family's decision regarding MAHN for religious or personal reasons, it is the responsibility of the nurse to request a change in assignment and for the healthcare system to ensure that a nurse who is comfortable in these situations can provide patient-centered care when MAHN is being withheld or withdrawn.

Conclusion

Food and fluid requirement changes in the terminally ill are frequently multifactorial in etiology and a naturally occurring, expected phenomenon. MAHN should be considered an intervention, rather than a basic provision of comfort. When a patient experiences a decreased desire to eat or drink as part of the end stage of illness, the patient along with the family may struggle to seek interventions to extend life, reduce the impact of possible symptoms such as hunger or dehydration, or fulfill a religious or cultural need at the end of life. Decisions about MAHN are complex and must be guided by the ethical principles of autonomy, beneficence, and nonmaleficence. Nurses need to understand the factors, such as religion and culture, which influence a patient's preferences. Nurses need to provide accurate and complete information about the benefits and burdens of MAHN to both the patient and other care team members. In doing so, nurses will ensure that decisions to initiate, withhold, or withdraw MAHN will be patient-centered. When the patient is no longer taking in hydration or nutrition in any form, nurses must be attentive to comfort and support for both the patient and family.

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CHAPTER 16

Dyspnea, Cough, and Terminal Secretions

DorAnne Donesky

Key Points

- Dyspnea management incorporates both attention to correction of the physiological defect causing dyspnea and interventions aimed at the common neurological pathway for dyspnea.
- People living with chronic dyspnea or cough should be encouraged to notice what works well for them in managing those symptoms using "*N* of 1" trials and then implement those strategies whenever the symptom recurs.
- Terminal secretions do not seem to bother the patient but can be distressing for family, friends, and caregivers. Education that normalizes the condition and reassures observers that the terminal secretions do not cause discomfort for the patient is important for minimizing distress of those who observe the condition.

Introduction

Breathing is the one vital body function that can be controlled consciously or can continue without any awareness or thought, completely subconsciously, when conscious attention is placed elsewhere. The breath is the focus of many spiritual traditions and serves as a bridge between the conscious and subconscious mind.[1] Attention to the breath as a method to optimize well-being has been documented since ancient times.[2,3] Conscious breathing is used to release stress and tension, build energy, support emotions, manage symptoms, improve physical and mental performance, and facilitate spiritual transformation.[4] Breathing is an important component of many mind–body therapies including yoga, guided imagery, and somatic grounding.[5] The respiratory system is a topic of interest for both popular self-help authors and basic, translational, and clinical researchers who are searching for ways to optimize the health and minimize the symptoms of patients living with serious illness.

We take breath for granted, we rarely think about it, but when something goes awry, it is the cause of serious panic and fear. Difficulty breathing feels dangerous and like a sign of impending suffocation in the setting of chronic lung disease.[6] Patients tend to stop their activity if they perceive danger, which leads to deconditioning and increased dyspnea over time in the vicious cycle of inactivity.[7] Patients with chronic dyspnea related to severe cardiopulmonary disease may live with dyspnea for many years and experience the stigma of a debilitating invisible disability.[8] Dyspnea correlates with mortality more than other measures such as pulmonary function.[9] Given its impact on depression, mortality, and quality of life (QOL), the importance of dyspnea has been recognized with the description of dyspnea as "the first vital symptom."[10]

The metaphorical significance of dyspnea has been recognized by the Life of Breath project (https://lifeofbreath.org/), which explores breath at the intersection of medicine, art, and the humanities—a medical humanities approach. The disciplines of anesthesia and engineering may also supplement the traditional work of pulmonology and palliative care in offering a new perspective on dyspnea management.[11] The purpose of this chapter is to review the current understanding of the pathophysiology, assessment, and management options for people living with serious illness who experience dyspnea, cough, or terminal secretions.

Dyspnea

Terminology of Breathing

Breathlessness, shortness of breath, and dyspnea are often used interchangeably when talking about the difficulty of breathing experienced by patients living with serious illness. Other terms include labored breathing or breathing discomfort. Dyspnea can be categorized into three primary groups. "Work" or "effort" is often used to describe the sensation of patients with impaired or fatigued respiratory muscles.[2] "Chest tightness" is used to describe the dyspnea experienced in asthma.[12] "Unsatisfied inspiration" or "air hunger" describes the sensation at the end of exercise or when breathing high levels of carbon dioxide.[13] In addition, breathless patients report anxiety, distress, discomfort, fear, and other negative terms when describing their breathing experience.[14]

The nomenclature for dyspnea continues to develop. Dyspnea can be acute or chronic, continuous or episodic, with variation in the timing and coping response.[15] Evidence is beginning to accumulate that chronic breathlessness, previously called *refractory breathlessness*,[16] is a distinct syndrome with unique neural activity in the brain which persists after treatment of underlying disease.[17] *Dyspnea crisis* is a term used for patients whose dyspnea overwhelms their ability to cope, but who do not want to return to the emergency department and undergo intubation and mechanical ventilation.[18] These crises often happen in the context of a patient who is living with chronic breathlessness.[15] The pattern of dyspnea is unique with each individual and includes both continuous and breakthrough dyspnea.[14]

Patient Experience

Dyspnea is one of the most distressing symptoms at the end of life[19] and occurs in the majority of patients diagnosed with chronic obstructive pulmonary disease (COPD), lung cancer, or heart failure.[14] Dyspnea is frequently also present in community-dwelling older adults who do not have any of the diagnoses traditionally associated with dyspnea.[20] The trajectory of dyspnea is distinct according to diagnosis; patients with COPD often experience moderate to severe fluctuating dyspnea for months with little change as death approaches, while many patients with cancer experience increasing dyspnea as they approach death, even if the cancer is not in the lungs.[21]

When people are living with chronic lung disease, their life can begin to revolve around their breathing needs. The case study details the personal experience of a woman living with idiopathic pulmonary fibrosis (IPF). Along with the dyspnea, there are many logistical challenges to living with chronic lung disease and dyspnea—the need for oxygen and coordination with the medical equipment company, learning to use an oximeter, potential weight gain or loss. Self-care activities focus on managing the physical manifestations of the illness, coping with the psychological effects, minimizing the social burden of the illness, and developing the knowledge and skills necessary to interact wisely with the health-care team.[22] Patients often feel stigmatized and blamed for their disease because of the association between smoking and lung disease, and the insidious onset of the disease often interferes with early initial treatment.[8] The uncertainty of the symptom contributes to fear and difficulties with coping.[14] Chronic breathlessness is frightening and distressing for both patient and family,[14] but evidence-based multidimensional interventions can provide relief.[23,24]

Case Study: A Patient Living with Idiopathic Pulmonary Fibrosis

Robin was 54 years old when she first noticed that it was difficult to take a deep breath. She was on a ski vacation and attributed it to the elevation. She developed a dry cough that was not responsive to treatment, and 5 years later, some abnormalities ("honeycombing") showed up on her chest x-ray. After several false diagnoses, she was told that she had idiopathic pulmonary fibrosis and enrolled in a clinical trial of an antifibrotic medication.

At first, the persistent cough didn't change much. She felt more fatigue and decreased stamina rather than shortness of breath, but 5 years after diagnosis, she first noticed shortness of breath while showering. For the next 7 years, she experienced progressively increasing bouts of dry cough and shortness of breath triggered by less and less activity. The dry cough got longer, more frequent, and intense. She began to use supplemental oxygen, cut down on her volunteer activities, and carried an oximeter with her.

Robin contracted influenza in January 2017, and she was left with a constant cough and sensation of sputum in her lower lobes. Her oxygen requirements increased considerably, she began to cough uncontrollably while walking, and she began to breathe through her mouth as she didn't feel like she could get enough air when breathing through her nose. She developed atrial tachycardia, which caused wide fluctuations in heart rate. During these episodes, she found that forcing herself to cough and laying on her bed with her head hanging over the side, below the level of the heart, would help her regain her equilibrium. She used large quantities of guaifenesin, nose blowing, water, and rest.

In the month before she died in November 2017, at the age of 68, she was very short of breath with minimal activities, and she required 10–15 L/min of oxygen to maintain an oxygen saturation of 90%. She was coughing at least hourly, and the coughing episodes lasted 2–5 minutes. She tried low-dose opioids for dyspnea management, but was concerned that her respiratory secretions became more difficult to expectorate. Up until the last week of her life, she was pleased with her QOL. She appreciated her scooter that gave her mobility (with her oxygen tanks) to attend her grandchildren's soccer games and dance recitals. She enjoyed the opportunity to move nearer her son for the last few years of her life, and she was satisfied with the "lasting good" she had done in this world.

Source: Excerpted from the writing of Robin Curley. Written October 31, 2017. Died November 15, 2017. Used with permission.

Pathophysiology of Dyspnea

Dyspnea is a complex phenomenon that includes the sensation of respiratory discomfort, an affective response to the sensation, and the impact on physical functioning and daily activities.[13] A beneficial model of breathlessness includes perception of both intensity and unpleasantness, emotional response, and functional consequences.[25] Many factors contribute to the sensation of dyspnea.[26] At its most basic level, the respiratory system is a pump that brings fresh oxygen to the tissues and removes carbon dioxide waste. The pump is activated by a neurological feedback system in communication with the musculature. The prevailing theory is that dyspnea results from a mismatch between respiratory demand and ventilatory mechanics,[27] an imbalance between the demand to breathe and the ability to breathe.[2] The automatic drive to breathe originates in the brainstem and communicates through a feedback system with the lungs and chest wall. When a mismatch occurs between the urge to breathe and actual ventilation, the brainstem communicates through a corollary discharge with the cortex and limbic regions of the brain, which triggers emotions, memories, abstract thoughts, and the evaluation and affective response to the dyspnea sensation.[9] A "final common pathway" of dyspnea, which is not linked to any specific etiology, may be explained by a central perception of breathlessness[27] triggered by the corollary discharge. The insular cortex, anterior cingulate cortex, and amygdala are areas in the brain that are active during breathlessness, as recognized by functional magnetic resonance imaging (fMRI) and positron emission tomography (PET) scanning. These areas are also active in the fear response and influence the emotional reaction to dyspnea.[28]

Any factors that increase the demand to breathe or reduce the body's ventilatory capacity may trigger a sensation of dyspnea (see Figure 16.1). Physical deconditioning may do both and is therefore a primary reason for dyspnea, regardless of whether other causes of dyspnea are present.[29] Physical deconditioning contributes to dyspnea, even in otherwise healthy adults.[20] People with dyspnea learn to limit their activities to minimize their dyspnea, leading to reduced muscle bulk and increased deconditioning and thus contributing to a vicious cycle of inactivity.[7]

Increased Respiratory Demand

Increased respiratory demand can be triggered by multiple factors. Metabolism naturally increases in the setting of exercise or fever, and the built-in reserves of the ventilatory mechanics can easily accommodate those usual demands. Systemic illness such as

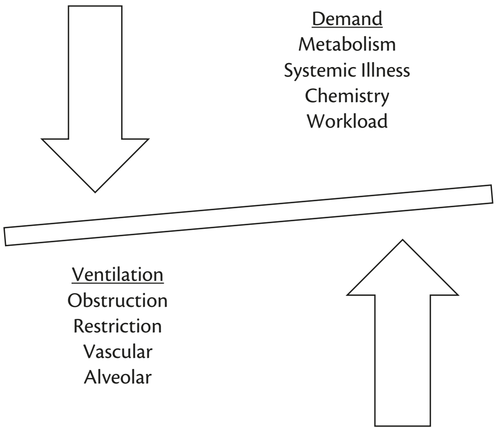

Figure 16.1 Imbalance between demand and ventilation.

hyperthyroid, sepsis, or cachexia also stimulate an increased demand on the respiratory system.[9] The muscle wasting of cachexia seen in COPD, heart failure, and cancer is linked to increased sympathetic drive, neurohumoral changes, and inflammation. The resulting skeletal muscle loss is independently associated with dyspnea, and exercise training possibly combined with nutritional supplementation may reverse breathlessness with the associated myopathy, exercise intolerance, and fatigue.[27]

A chemical imbalance between oxygen and carbon dioxide in the blood will also increase the respiratory demand. In anemia, the decreased hemoglobin available to carry oxygen prevents the cardiovascular system from supplying adequate oxygen to the tissues.[9] The healthy body can accommodate when traveling to altitude, but the lower oxygen concentration increases the respiratory demands on the body. In hypercapnic respiratory failure, the body's respiratory demand to expire carbon dioxide overwhelms its ventilatory capabilities and carbon dioxide builds up in the blood, leading to life-threatening respiratory acidosis.

Anything that increases the external workload on the respiratory system will increase respiratory demand and may fatigue the muscles beyond their ability to function. Obesity increases the body's requirements for respiration. Carrying heavy equipment or using the accessory respiratory muscles when they are needed for respiration may also overwhelm respiratory demand beyond its reserve capacity. Neuromuscular disorders increase the workload relative to the body's ability to move the respiratory pump, given reduced muscular strength and/or neurological input. Multiple sensory receptors throughout the respiratory system monitor lung mechanics, chemistry, and respiratory muscle function[2] and provide feedback to the brainstem respiratory centers when breathing adjustments are necessary to correct or maintain optimal respiratory function.

Reduced Ventilatory Capacity

Problems with airway obstruction, a restrictive defect, vascular problems, or fluid build-up in the air sacs can interfere with ventilation or gas exchange. In these situations, the body is not able to supply enough ventilation to meet the demand.[26] Obstruction occurs when something is preventing the movement of air, usually on exhalation. The obstruction can be caused by mucus build-up or constriction of smooth muscle surrounding the airways, which is often the case with asthma or chronic bronchitis. Obstruction also occurs when the air sacs/alveoli responsible for gas exchange are damaged and no longer able to function, such as what occurs with emphysema, or filled with fluid due to pneumonia or pulmonary edema. A mechanical obstruction can occur when a tumor or scar tissue blocks either the upper or lower airways. When obstruction continues over time, the lungs may become hyperinflated when exhalation does not match the volume of inhalation, thus reducing the space available in the lung for movement of air.

A restrictive pulmonary defect either prevents the lungs from expanding completely or requires additional effort to expand the lungs. The restriction can occur because of decreased compliance of the lung tissue where the lungs become stiff from a condition such as fibrosis or scarring. The pleural space and lining of the lung may be restricted due to plaque, or the restriction may be external due to obesity, kyphoscoliosis, or neuromuscular disease.

Common pulmonary vascular disorders include pulmonary emboli and pulmonary hypertension. Pulmonary emboli interrupt blood flow in a pulmonary artery. Small emboli may interrupt perfusion of blood into the capillaries surrounding the alveoli, causing a mismatch between ventilation and perfusion.[30] Large catastrophic pulmonary emboli may interrupt blood flow to an entire region of the lung and cause immediate death. Pulmonary hypertension may be idiopathic, genetic, drug-induced, or secondary to connective tissue or other cardiopulmonary diseases that increase blood flow to the lungs. Lymphadenopathy, superior vena cava obstruction, and ascites are complications of other serious illnesses that can also contribute to dyspnea.[9]

Pneumonia or pulmonary edema may interrupt ventilation when the alveoli fill with fluid or exudate, preventing the oxygen from entering the alveoli and reaching the capillaries. Pneumonia may be caused by bacteria, viruses, toxins, or aspiration. Pulmonary edema occurs when hydrostatic pressure from fluid overload moves fluid from the vascular space into the interstitial space and alveoli.

Final Common Pathway of Dyspnea

Breathlessness related to the physiology of the lungs, chest, airways, and blood vessels can be addressed by correcting the mismatch between respiratory demand and ventilatory mechanics. When breathlessness remains after the mismatch has been addressed, the breathlessness may be related to central neurological processing and perception, the "final common pathway," as confirmed by fMRI and PET imaging studies focused on the emotion-related areas of the insula, anterior cingulate cortex, and amygdala in the brain.[28]

The final common pathway of dyspnea may contribute to *symptom clusters*, the coexistence of two or more concurrent symptoms that may have a common cause.[31] Symptoms can occur because of the disease itself, treatment side effects, or comorbidities.[31] As serious illnesses progress, interventions may benefit the multiple symptoms in a symptom cluster simultaneously due to a shared common symptom pathway. Pain and dyspnea often coexist, frequently in the context of depression and functional impairments, and symptom-specific interventions may also relieve the other symptoms in the cluster.[20] A symptom cluster of cough, breathlessness, and fatigue has been identified in lung cancer.[32] Dyspnea has been correlated with anxiety, depression, fatigue, and cough.[33] Distress related to dyspnea is associated with symptom clusters that include fatigue and nausea.[34] Attention to both the mismatch between respiratory demand and ventilatory mechanics and the final common pathway of dyspnea provides keys to both measurement and interventions for dyspnea.

Measurement of Dyspnea

Patient-reported outcomes are the foundation of dyspnea measurement as no physiological correlate has been identified that accurately predicts dyspnea.[26] Dyspnea scales measure one or more of the sensation of respiratory discomfort, an affective response to the sensation, and the impact on physical functioning and daily activities (see Table 16.1).[13] When only one aspect of dyspnea is measured, unidimensional scales typically measure the intensity of the sensation. Scales such as the visual analogue scale (VAS), Borg scale, and numeric rating scale (NRS) can be used to measure intensity or distress related to the symptom. These scales are easy to implement in a clinical setting and familiar to patients who have often used similar scales for other purposes. Given the importance of the three domains of dyspnea, the Multidimensional Dyspnea Profile (MDP) was developed to measure sensory and affective dimensions of dyspnea.[35,36] It is easy to administer, acceptable to nurses for administration in the clinical setting,[37] and responsive to change over time. Identification of patients with a strong affective dimension to their dyspnea through the use of the MDP may provide a new target for interventions or optimize selection of interventions that are likely to benefit the affective component.[38]

With the modern development of psychometric theory, several short scales have been developed that provide additional information with minimal patient burden. The Dyspnea-12 (D-12) rates dyspnea using commonly used descriptive terms.[39] Both the MDP and D-12 provide a multidimensional assessment of dyspnea; the D-12 provides one single breathlessness severity score within the context of daily life while the MDP separates sensation and emotion.[40] The Shortness of Breath with Daily Activities Questionnaire (SOBDA) assesses dyspnea in COPD with 13 common activities.[41,42] The Dyspnea Management Questionnaire has a computer-adaptive test capability to measure intensity, anxiety, activity avoidance, and self-efficacy.[43] The Functional Assessment of Chronic Illness Therapy-Dyspnea (FACIT-Dyspnea) scale is a 10-item scale using interactive response technology methods to rate dyspnea with a variety of activities. The FACIT questionnaires are available free of charge on the FACIT website (www.facit.org).[44,45]

Early dyspnea research typically used psychometrically sound instruments that were not easily translated into the clinical setting because of their length and subject or provider burden. The Baseline/Transitional Dyspnea Index (BDI/TDI) assesses severity of dyspnea and change over time, taking functional impairment into account.[46] The UCSD Shortness of Breath Questionnaire rates dyspnea during a variety of common activities.[47,48] The dyspnea domain of the Chronic Respiratory Questionnaire quantifies dyspnea as a component of QOL.[49,50]

Because patients often experience dyspnea only with activities, tools have been designed that quantify the impact of activity on dyspnea. The modified Medical Research Council Dyspnea Scale is a simple, classic, four-level tool that categorizes dyspnea according to activity level. This tool is not very sensitive to change over time so it is used to categorize patients according to symptom severity but not to document dyspnea improvement in intervention research.[51,52] The American Association of Cardiovascular and Pulmonary Rehabilitation has developed an outcomes toolkit to guide clinicians and researchers in selecting the best instruments for their projects. The AACVPR toolkit includes measures of functional status, exercise capacity, dyspnea, health-related QOL, and psychosocial tools with information about psychometric properties, clinically important differences, and brief description of each tool.[53] For patients who are not able to provide self-report, the validated Respiratory Distress Observation Scale provides an objective measure using respiratory and behavioral signs that have been correlated with dyspnea.[54,55]

When a brief overview of a variety of symptoms is needed for clinical practice or for the assessment of symptom clusters, dyspnea can be assessed as part of a symptom assessment survey. The Edmonton Symptom Assessment Survey (ESAS) is commonly used in palliative care and includes a 10-point NRS for nine symptoms including dyspnea.[56] ESAS has been validated in many languages other than English.[57–60] The Memorial Symptom Assessment Scale (MSAS) evaluates the intensity, frequency, and distress of 32 symptoms including dyspnea,[61,62] and validated translations of MSAS are also available in multiple languages.[63–66]

When measuring dyspnea, response shift,[67] the variety of available tools, and the effect of attention to the symptom are important factors to consider. Many patients subconsciously decrease their activity levels to cope with dyspnea, termed "response shift,"[67] so their actual dyspnea scores may not change but further inquiry into their current activity levels in comparison to several years prior may reveal dyspnea as the reason for reduced activity levels. The variety of available dyspnea tools provides the clinician or researcher with choices that can meet the needs of their individual project, but the variety also interferes with the ability to do meta-analyses or systematic reviews. There is a question on whether it is good to measure dyspnea or whether attention to a symptom causes increased distress from that symptom.[68] Increased suffering from the additional awareness of dyspnea may be an unintended consequence of measuring dyspnea.[27]

Interventions for Dyspnea

When considering management options for patients with dyspnea, the first consideration is to target specific mechanisms of dyspnea as correcting the physiological defect will often improve dyspnea.[27] After optimizing the pathophysiology of the symptom, dyspnea management strategies ultimately may provide relief through their effects on the central common pathway of dyspnea. With a focus on evaluating interventions where dyspnea was specified as an outcome, a task force of the Hospice and Palliative Nurses Association (HPNA) presented a review of the evidence available through December 2016 at the 2017 HPNA/American Academy of Hospice and Palliative Medicine Annual Assembly.[69] The strongest evidence supported long-acting beta agonist (LABA) combined with long-acting muscarinic antagonist (LAMA) inhaler therapy, immediate-release oral morphine, oxygen for patients with COPD or hypoxemia, pulmonary rehabilitation (PR), and specialist dyspnea service. Although the evidence is not as strong, short-acting beta agonist (SABA) and short-acting muscarinic antagonist (SAMA) inhalers, other forms of opioids, acupressure, fans, dyspnea self-management programs, and transcutaneous electrical nerve stimulation (TENS) of acupressure points are likely to be effective. Interventions that may be considered on an individual basis, balancing benefit with harm, include noninvasive ventilation, high-flow nasal oxygen, acupuncture, and co-enzyme Q10. The effectiveness of benzodiazepines, Heliox (a mix of helium and oxygen), and mindfulness for dyspnea management has not been established. Nebulized furosemide or morphine are unlikely to be effective for dyspnea relief. Many gaps in the literature exist, including populations beyond COPD and cancer, routes of delivery, alternate formulations, timing and dosage, safety profiles,

Table 16.1 Dyspnea measurement instruments

Name	Description	Considerations
Unidimensional Scales		
Borg-CR scale	Category ratio (CR) scale measures intensity of experience, using verbal anchors related to numbers	Requires permission from author for use (www.borgperception.se)
Numeric rating scale (NRS)	Eleven point scale from 0 to 10 for self-report of symptom experience	Commonly used for pain so many patients are familiar with NRS Can be used with any symptom or term
Visual analogue scale (VAS)	100 mm horizontal line with "none" on the left end of the line and "very severe" on the right end. Subjects select a place on the line to represent their subjective experience of the symptom.	Numbers are not placed along the line. VAS score is 0 to 100 but the subject is not aware of the numbers. Can be used with any symptom or term (distress, discomfort)
New Generation Dyspnea Measurement (since 2010)		
Dyspnea-12	Rating of breathlessness with 12 items	Extensive validity testing has been done
Dyspnea Management Questionnaire	Computer adaptive test with test bank of 71 items for multidimensional measurement; maximum of 20 items required to obtain subscale scores.	Questions are selected based on respondent's answers to previous questions Four subscales: dyspnea intensity, anxiety, activity avoidance, and activity self-efficacy.
Functional Assessment of Chronic Illness Therapy (FACIT)-Dyspnea	Seven-day recall developed using item response theory	Dyspnea is one scale in the FACIT measurement system. More information available at www.facit.org A 10- or 33-item version is available English version is free; multiple other languages available
Multidimensional Dyspnea Profile (MDP)	Measurement of the sensory and affective dimensions of dyspnea during a specific event or time.	Designed for both clinical and laboratory research Not disease specific Administration takes 1–3 minutes
Shortness of breath with daily activities questionnaire (SOBDA)	Evaluates dyspnea in patients with COPD in relation to 13 common physical activities, using e-diary	Developed as a patient-reported outcomes instrument for use in clinical research Development funded by GlaxoSmithKline
Classic Dyspnea Measurement (prior to 2000)		
Baseline/Transitional Dyspnea Index (BDI/TDI)	Interviewer-administered dyspnea rating according to functional impairment and magnitude of both task and effort. TDI assesses change from baseline. BDI range from 0 (severe) to 4 (unimpaired) and TDI ranges from −9 (deterioration) to +9 (improvement)	Request permission for use from donald.a.mahler@hitchcock.org Available in 73 languages More information available at http://mapi-trust.org/questionnaires/bdi-tdi/
Chronic Respiratory Disease Questionnaire (CRQ) –Dyspnea subscale	One of four subscales in a self-report or interviewer-led quality of life instrument.	Sensitive to change with interventions
Modified Medical Research Council (mMRC) dyspnea scale	Quantifies disability related to dyspnea on a 5-point scale with lower number indicating less dyspnea	Public domain May have low sensitivity to change In use for more than 50 years
UCSD Shortness of Breath Questionnaire	Rating of breathlessness on 6 point scale for 24 activities of daily living. Range from 0 to 12 with lower scores indicating greater breathlessness	Copyright by University of California Free to use with permission and acknowledgment for education and research
Dyspnea Proxy Measurement for Nonverbal Patients		
Respiratory Distress Observation Scale (RDOS)	Behavioral evaluation of 8 physical signs associated with respiratory distress when a patient is not paralyzed but unable to self report.	A 2-point change (out of 17 total points) indicates meaningful change in the patient's condition
Symptom Surveys		
Edmonton Symptom Assessment System (ESAS)	Quantitative assessment of 10 symptoms that allows for simple and rapid documentation of multiple patient-reported symptoms at the same time	Commonly used for screening and monitoring in palliative care Multiple permutations exist
Memorial Symptom Assessment Scale (MSAS)	Assessment of severity, frequency, and distress for 26 symptoms, and severity and distress for 6 symptoms when frequency is not important	Subscales include physical distress, psychological distress, and The Global Distress Index Short form includes 32 symptoms and one dimension Condensed version has 14 symptoms and one dimension

and variations across the disease trajectory. The search strategy did not yield literature related to nonpharmacologic therapies such as breathing strategies,[70] energy conservation,[71] cognitive behavioral therapy,[72] or yoga.[73]

The concept of "total dyspnea,"[74] which acknowledges the multiple components of distress related to dyspnea and incorporates the meaning of the symptom within a context of whole-person care, provides a rationale for the value of pharmacological, mechanical, and behavioral dyspnea management strategies that address patient suffering in the psychological, social, and existential as well as physical realms. Quality of care for patients with dyspnea includes attention to dyspnea intensity, distress, functional impact, and qualitative descriptors that may distinguish causes of dyspnea.[75]

Pharmacological Strategies

Beta agonist and muscarinic antagonist inhaler therapies are the mainstay of treatment for many patients with chronic lung disease, especially COPD. Inhaled medications can be administered by nebulizer, metered-dose inhalers, dry powder inhalers, or soft mist inhalers. Characteristics of the device, patient capabilities, and optimal technique are all important considerations when selecting inhaled medications.[76] Although oral steroids may be beneficial for dyspnea relief near end of life,[77] the systemic side effects may not be worth it for people who are not imminently dying. Opioids are a mainstay of pain management in palliative care, and low doses of oral or parenteral opioids are also beneficial for dyspnea management.[54] The beneficial effects on dyspnea of opioids and oral steroids may be synergistic when used in combination.[78]

Oxygen therapy may be beneficial for dyspnea and even prolong life in patients with hypoxemia,[79] but the mortality benefit is not present in patients with mild hypoxemia at rest (SpO_2 89–93%) or during exercise (SpO_2 80–89% for no more than 5 minutes during a 6-minute walk).[80] Nasal high-flow oxygen therapy may be useful for improving lung mechanics and for short-term emergency treatment of dyspnea.[81,82] As end of life approaches and comfort becomes the primary focus, maintaining oxygen saturation is no longer the goal, and a fan or pursed lip breathing may be more advantageous.[83]

Opioids have become an important foundation for treatment of chronic dyspnea after medical therapy focused on the underlying pathophysiology has been optimized. Concerns arising from the opioid epidemic have encouraged the search for other medications that can be used for dyspnea management.[84] The increasing focus on the central neural pathway of dyspnea has renewed interest in alternative and repurposed medications that can reduce chronic dyspnea through effects on the dyspnea pathway. Several classifications of medications including anxiolytics, antidepressants, antihistamines, cannabinoids, and herbal-based treatments have been studied but evidence is insufficient to recommend them for dyspnea treatment.[84] The question has been raised whether opioids might improve exertional dyspnea if taken prior to exercise,[7] and further research is required to answer that question. Recent evaluation of patient-controlled therapy for breathlessness resulted in less administration of total opioid dose over time and better control of breathlessness.[85] Another innovative possibility that might prove beneficial for the palliative relief of dyspnea may be very-low-dose ketamine, which has been shown to decrease the body's response to hypercapnia.[86]

Mechanical

Patients with serious life-threatening illness increasingly seek palliative care concurrently with pursuing surgical interventions for their lung disease. In addition to mechanical ventilation that is used to relieve respiratory distress,[87] surgical and bronchoscopic procedures may be appropriate for some patients with dyspnea. Lung volume reduction surgery has been shown to improve dyspnea, exercise tolerance, and survival in patients with predominantly upper lobe emphysema and low exercise capacity.[88] A variety of noninvasive endoscopic options for lung volume reduction are now available, including the use of bronchial valves, coil implants, and thermal vapor ablation.[89] These therapies may be appropriate considerations for patients with dyspnea primarily related to lung hyperinflation.[90] Patients with emphysema, pulmonary fibrosis, cystic fibrosis, pulmonary hypertension, bronchiectasis, and other diagnoses[91] experience improvement in dyspnea after lung transplantation.[92]

When the lung is not able to expand because of a malignant pleural effusion or a trapped lung due to pleural fibrosis or inflammation, relief from dyspnea may occur with the placement of a tunneled pleural catheter to drain excess fluid into the abdominal cavity, pleurodesis to adhere the lung to the chest wall and prevent future build-up of fluid, or decortication (removal of restricting tissue) by video-assisted thoracoscopy.[93,94] Patients may experience obstruction of the central airways due to tumors or stenosis. Airway stents, balloon dilatation, laser ablation, cryotherapy, or radioactive brachytherapy may provide symptomatic relief in those situations.[95]

The ideal role for noninvasive ventilation for the palliation of dyspnea is still being explored.[96,97] High-intensity positive pressures, using the highest inspiratory pressures that the patient can tolerate, may provide more dyspnea relief, improvement in hypercapnia, and improved mortality above that experienced with the usual low-intensity noninvasive ventilation.[98] Other noninvasive mechanical interventions to consider for airway clearance and optimal breathing are oscillatory positive pressure devices such as the Acapella, Flutter, or Aerobika[99]; autogenic drainage[100]; active cycle of breathing[101]; and high-frequency chest wall oscillation.[102] Although the evidence is not strong for any of these noninvasive options, an "*N* of 1" trial with careful consideration of the risk–benefit analysis may be beneficial for people living with breathlessness.[103]

Behavioral

Dyspnea is a complex multifactorial symptom, and therefore complex interventions are often necessary to adequately address the multiple causes of the symptom. Pulmonary rehabilitation (PR) is an interdisciplinary program that combines exercise training, patient education, and psychosocial support in a comprehensive evidence-based intervention for patients with lung disease.[104] PR classes typically meet 2–3 times per week for several hours per session over a 6- to 12-week interval. Some PR programs also provide maintenance exercise indefinitely after the completion of the initial program. PR shares many similarities with palliative care in its focus on symptom management and QOL. The foundation of PR is exercise training, whereas palliative care integrates more of a focus on advance care planning and the spiritual dimension of health.[105] Now that palliative care is recognized as a valuable treatment for patients across the spectrum of serious illness, it makes sense to get palliative care involved earlier, soon after PR and as soon as

Table 16.2 Nonpharmacological interventions for dyspnea

Professional	Self-management	Complementary
Pulmonary rehabilitation	Posture: braced forward lean	Relaxation/Mindfulness-based Stress Reduction (MBSR)
Breathlessness intervention	Pursed lip breathing	Biofeedback
Pacing/Energy conservation	Abdominal breathing	Spinal movement
Cognitive Behavior Therapy (CBT)	Fan/Air movement	Acupuncture/acupressure
Music/Distractive auditory stimuli	Exercise	Yoga/Tai Chi/Qigong
Chest wall vibration	Acceptance	Branch-chain amino acids
Noninvasive ventilation	Socialize	
Education		
Walking aid: rollator/cane		
Dyspnea plan		
Neuromuscular electrical stimulation		

patients are symptomatic. The beneficial outcomes following PR decline over time, and perhaps palliative care follow-up after PR would support maintenance of PR outcomes over time.

Despite the attention that dyspnea management has received in the literature, patients and their families spend many hours on their own between medical appointments coping with dyspnea to the best of their abilities. Self-management is still the primary mainstay of dyspnea treatment.[22] Activated patients who embrace their own personal initiative and engagement can increase their independence and QOL in the presence of their dyspnea.[6] Patients report many strategies for managing their symptoms, and very few of those strategies include evidence-based or medically prescribed interventions. Patients find themselves strategically planning their daily activities, using creative thinking and assistive devices to accomplish their daily tasks.[22] Integrating exacerbation action plans in self-management interventions improves health-related QOL and decreases the probability of hospitalization.[106]

Several excellent models and treatment algorithms for dyspnea management have been published.[6,9,103] Principles of high-quality dyspnea management can be applied in all settings, and the treatment algorithms are similar even in the emergency department.[107] Many interventions have minimal effect on their own but contribute to a cumulative benefit when used in combination.[26] Nonpharmacological and complementary therapies are recommended if they have research evidence to support them[108] or if the safety profile merits an "*N* of 1" trial with minimal concern.[103] (See Table 16.2 for a list of nonpharmacological professional, self-management, and complementary therapies to consider.) Most of the nonpharmacological and complementary therapies that patients use or providers recommend for dyspnea management are focused on the central pathway of dyspnea. Interventions focused on anxiety, depression, and other symptoms commonly found with dyspnea in symptom clusters can be beneficial for improving dyspnea as well.[30]

When patients living with chronic dyspnea experience a dyspnea crisis, the sense of helplessness experienced by family caregivers contributes to the distress caused by dyspnea.[14] Patients at risk for dyspnea crisis can plan in advance with their families so that when a dyspnea crisis occurs, each family member will have a practiced response that will normalize the experience, decrease the panic, and quickly institute predetermined strategies that will mitigate the breathing crisis.[18] A "dyspnea plan" can include both pharmacological and nonpharmacological measures and rituals to enact when dyspnea crisis occurs.[6]

Several outpatient dyspnea clinic models have been tested with promising results.[23,24] Complex interventions for breathlessness assess both the sensory and affective components and focus on modulating the central perception of breathlessness regardless of the original pathophysiology of the symptom. The interprofessional team assists patients to manage their affective response to the symptom while still addressing the original pathophysiology of the illness that caused the symptom. The "softer skills" such as empathic listening in the context of new service models may provide relief for dyspnea.[11]

The interprofessional team offers unique perspectives related to dyspnea management interventions. From a physical therapy perspective, physical conditioning, reassurance, positioning, and explanations of the anatomy and physiology related to breathing strategies are effective means to support patients in managing their dyspnea.[109] Occupational therapists use energy conservation and supervised practice to support patients in maintaining their everyday activities.[110–112] Although respiratory therapists have traditionally practiced in hospital settings, their experience in leading PR programs demonstrates their expertise in supporting dyspnea management within a whole-person context.[113–115] Given the ubiquity of dyspnea within the healthcare system, it makes sense to educate allied health providers and health coaches on strategies specific to dyspnea management.[116,117] Successful interventions for dyspnea benefit from multiple perspectives.

Cough Physiology, Measurement, and Interventions

Despite cough being a very distressing symptom that interrupts social situations and is physically exhausting,[118] no interventions are consistently effective in treating cough. Over time, cough can affect physical, mental, and social health. It interferes with sleep, fatigues the muscles, interferes with vocal quality, and contributes to urinary incontinence.[119] Cough is one of the most common symptoms that spur medical visits.

Pathophysiology of Cough

The cough reflex in the brainstem protects the airways from mechanical or chemical irritants mediated by sensory nerves in the large and peripheral airways. Voluntary cough and the urge to cough are centered in the cerebral cortex.[119] Early brain imaging evidence suggests that the conscious regulation of cough occurs in brain regions and neural pathways that are separate from the urge to cough. Both the voluntary and the reflex pathways are involved in cough control.[120] Overlap with the descending inhibitory pathways related to other stimuli may explain why cough is suppressed in the presence of other stimuli.[121] Cough is stimulated by mechanical (airway size), biochemical (capsaicin), and neurosensory changes.[119] Irritation can be caused by the presence of pathology in the airways, parenchymal inflammation from treatment, heightened cough reflex sensitivity, or comorbidities such as gastroesophageal reflux disease (GERD) or sinusitis.[121] With hypersensitivity, even minimal irritation such as laughing, talking, or temperature changes can lead to cough.[121] Other irritants include smoking and perfume. Central processing may occur in several brain regions.[119]

The most common causes of cough are smoking, lung pathology such as asthma, postnasal drainage (PND), GERD, and medications.[120] New pathologies have been identified for cough. Obstructive sleep apnea can manifest with cough, possibly because of pressure buildup in the upper airway which may increase diaphragmatic pressure and contribute to GERD; treatment with continuous positive airway pressure (CPAP) can alleviate the cough. Cough from enlarged tonsils can be treated with tonsillectomy. Other unusual sources of cough might be protracted bacterial bronchitis; basidiomycetes fungus, treated with antifungal medications; cervical spondylosis; and abnormal salivary glands at the base of the tongue.[122] *Cough hypersensitivity syndrome* (CHS) signifies neuronal activation, sensitization, and/or dysfunction which leads to excessive coughing.[123] Chronic dry cough is very common in IPF, possibly due to traction of the parenchyma related to fibrosis.[119] GERD may cause microaspiration of acid and reflux of gastric contents into the airways. Medications such as angiotensin converting enzyme (ACE) inhibitors and beta blockers have been associated with cough.[119] Chronic lung disease such as COPD/emphysema or infection can also contribute to chronic cough. Chronic sinusitis and postnasal drip (PND) syndrome may be asymptomatic, or patients may not notice PND which can contribute to chronic cough.[119] Cough can also be the first sign of lung cancer. The recognition of laryngeal irritability and chronic hypersensitivity has led to the idea that cough is a sensory neuropathy.[120] Other triggers include foods, smells, laughing, and laryngeal dysesthesia or "tickle" in the throat.[120] Sensory neuropathic cough may present with chronic cough, laryngospasm, or paradoxical vocal cord dysfunction.[120]

Cough can be completely voluntary and under conscious control, completely reflexive in response to a stimulus, or a combination of reflexive and voluntary. Reflexive coughing can become more pronounced as a person becomes sensitized to a given stimulus. Sensitization is triggered by inflammatory mediators that may be released after exposure to viruses, antigens, or inhaled toxins like cigarette smoke.[123]

Measurement of Cough

Intensity, frequency, and disruptiveness are components of cough that should be measured.[124] VAS subjective scales are easy to use for each component. Several instruments including the Leicester Cough Questionnaire[125] and the Cough Specific Quality of Life Questionnaire[126] measure the global impact of cough. A seven-item Cough Severity Diary has been tested in patients with chronic and subacute cough.[127] Objective measurement of cough has been attempted with ambulatory cough monitoring (ACM) such as the Leicester Cough Monitor and the VitaloJAK (Vitalograph, Inc., Lenexa, KS).[128] Although objective measurement is intuitively attractive, many threats to validity exist including the difficulty in distinguishing cough from other sounds, determining the marker of severity, and objective quantification. Perhaps both subjective and objective measures need to be assessed together.[121]

Cough can be divided into acute, subacute, and chronic cough.[122] Cough hypersensitivity syndrome encompasses chronic idiopathic cough, chronic refractory cough, and sensory neuropathic cough.[120] Recent guidelines for the evaluation and treatment of unexplained chronic cough provide an assessment algorithm.[129] Sputum eosinophils or exhaled nitric oxide should be evaluated to identify patients with bronchial hyperresponsiveness who might respond to inhaled corticosteroids.[129]

Interventions for Cough

The goal for cough treatment is to allow normal cough while blocking pathological cough.[123] Many therapies have been suggested for cough, seemingly because none of them work very well. It may be that cough appears to be one entity but actually has multiple causes that have not yet been identified or linked to an effective intervention. Behavioral cough control techniques and vocal hygiene strategies taught by a speech therapist may reduce cough symptoms.[130,131] Additional strategies may include pursed lip breathing, swallowing to diminish the urge to cough, avoiding smoking and mouth breathing, minimizing alcohol and caffeine, increasing water intake, or using steam inhalation.[130]

The CHEST Expert Cough Panel is developing clinical practice guidelines as living documents that are continually updated as new evidence, technologies, and recommendations become available.[132] For cough in adult patients with lung cancer, they recommend a stepped approach starting with the identification and treatment of coexisting causes of cough, nonpharmacological cough suppression exercises, endobronchial brachytherapy, and graduated trials of various cough suppressants.[133] Although many substances including glaucine, Chinese herbs, Duopect, moguisteine, pipazethate, guaifenesin, N-acetylcysteine, diphenhydramine, loratadine, erythromycin, ipratropium, and inhaled corticosteroids have been tested as antitussives, codeine and dextromethorphan are the only two agents that have been shown to reduce frequency and severity of chronic cough.[134] Slow-release morphine and dextromethorphan, which is a codeine analog, both act centrally to inhibit the cough reflex. Thalidomide has been tested for cough because of its anti-inflammatory properties, but the side effects are severe, including birth defects and sensorimotor peripheral neuropathy. With the recognition that cough may be triggered by sensory neuropathic cough or laryngeal irritability, neuromodulators used to treat neuropathic pain, such as gabapentin, pregabalin or amitriptyline, may be helpful.[120]

Disease-directed treatment for cancer-related cough may include drainage of pleural effusions, brachytherapy (radiation in direct contact with tissue), or photodynamic therapy.[130] A Cochrane review of randomized controlled trials (RCTs) for cancer-related cough treatment found minimal evidence but suggested that pharmacologic treatments like butamirate linctus, codeine 60 mg, morphine, dihydrocodeine, cromoglycate, and hydropropizine or levodropropizine may be beneficial for cough.[130] Given the low level of evidence and the age of the research, proposed recommendations for palliative cough management balance risk with benefit. The first step is to consider disease-directed treatment and review medications to see if any might be exacerbating the cough. Evaluate and treat any comorbidities that may be contributing to cough. Then consider sodium cromoglycate, which is relatively safe but supported only by minimal evidence. If still not responsive, consider opioid derivatives such as morphine, codeine, or dextromethorphan.[118]

In patients with unexplained cough that has not responded to a trial of inhaled corticosteroids, speech therapy and gabapentin trials are recommended.[129] A recent systematic review of treatments for cough related to the common cold found many treatment options available, but the evidence was not compelling for any of the options. The evidence was not strong enough to support recommendations for decongestants, antihistamines, acetylcysteine, nonsteroidal anti-inflammatory drugs (NSAIDs), honey, zinc lozenges, over-the-counter (OTC) antitussives, expectorants, mucolytics, or combination products.[135] The evidence base has not changed since previous guidelines were published in 2006, and the majority of the research on cough interventions was published before 2000.[134]

Terminal Secretions: Physiology, Measurement, and Interventions

Many terms are used to describe terminal secretions, usually including phrases such as "movement of bronchial secretions," "noisy breathing," or "sound in relation to respiration."[136] These secretions occur in the terminal phase of illness and are distressing for professional and family caregivers. The study of terminal secretions is inhibited by ethical concerns about randomizing dying patients who may not be able to give consent or share their perspective.[137] Does anyone know what it feels like to have terminal secretions? We have strong opinions on how to manage it, but we don't really know for sure because no one can tell us that the interventions were helpful or not.

Pathophysiology of Terminal Secretions

Terminal secretions, also called "death rattle," are caused by breathing through secretions in the upper airways as a patient approaches death and is no longer able to clear the secretions through swallowing or coughing.[137] The tongue may also cause obstruction and contribute to noisy breathing in patients who are nearing end of life.[137] Most patients die within 48 hours after developing terminal secretions.[138]

Hipp and Letizia propose that brain hypoxia causes ongoing release of acetylcholine from the parasympathetic nervous system, which activates the salivary and bronchial glands, leading to excessive secretions. Inability to swallow, weakened gag and cough reflexes, and decreased level of consciousness all contribute to the development of noisy breathing.[139] Dehydration may make secretions more tenacious and difficult to clear, especially in the setting of dysphagia and decreased mental status.[140] Noise during respirations occurs when the movement of air disturbs the oropharyngeal secretions, and the sound is amplified through the mouth and nasal passages.

Measurement of Terminal Secretions

Terminal secretions can be caused by excessive oral and salivary secretions, also termed type 1 or "real" death rattle. It occurs when the patient's level of consciousness has decreased and seems to be amenable to anticholinergic treatment. Type 2 or "pseudo" death rattle is caused by bronchial secretions that are formed due to pulmonary pathology such as infection, aspiration, or edema. Type 2 secretions are not as amenable to anticholinergic treatment and can be very distressing as the patient may be conscious when experiencing these secretions.[141] A combination of both types of terminal secretions may occur. The Victoria Respiratory Congestion Scale (VRCS) has been developed to quantify terminal secretions and noisy breathing using a 0–3 scale depending on the distance at which noisy congestion is audible.[141]

Interventions for Terminal Secretions

Antimuscarinic (most anticholinergic agents act on muscarinic acetylcholine receptors) medications are typically used to decrease secretions, but their efficacy is questionable. Perhaps they would be better used as preventive measures and started early, prior to the development of terminal secretions, since anticholinergic drugs do not remove existing secretions but prevent the formation and accumulation of secretions after the medication has been initiated.[142] Another option to maximize treatment might be to gently suction the secretions prior to beginning anticholinergic treatment.[143] Side effects such as urinary retention and dry mouth are problematic for patients near the end of life.[137] Withholding hydration is another management technique that was the focus of an observational study. No difference in terminal secretions was found after withholding hydration, although those in the nonhydration group experienced less frequent peripheral edema, pleural effusion, and ascites.[144] Guideline-based hydration improved family satisfaction and may decrease terminal secretions at end of life.[145]

Although the evidence in favor of anticholinergic therapy is weak,[136,146] such therapies are regularly used in clinical practice so Bennett and colleagues developed an evidence-based guideline that outlines the characteristics and considerations of each of the available anticholinergic options.[140] Specific information regarding dosage and cost were published by Brock and colleagues.[147] Nonpharmacological interventions to reduce terminal secretions and noisy breathing include repositioning, suctioning, and restricting medically administered hydration, although these interventions have not been scientifically studied. Educating the family about behavioral indicators that affirm the absence of distress can be very helpful. The phrase "death rattle" can be distressing, and other terms are preferable in discussions with families.[148] Although nurses often worry about the meaning of terminal secretions for family members, many families actually express relief that the terminal secretions indicate that the patient will soon be done with suffering.[149] Staff education can lead to higher quality care of patients with terminal secretions and also preserve scarce resources with lower cost options.[147] Both families and staff can find terminal secretions to be distressing, although the distress can be relieved with careful education that the patient is not uncomfortable, it is a normal part of the dying process for many people, and it won't last long. Many times, families get their cues from the staff on whether or not to be distressed by situations such as terminal secretions.[147]

Conclusion

When faced with patients experiencing dyspnea, cough, terminal secretions, and associated distress caused by cardiopulmonary, neuromuscular, or metastatic disease, the goal often becomes eradicating or managing the symptom. In the context of the bothersome respiratory conditions that are often present in patients receiving palliative care, it is possible to achieve a positive sensation of breathing, relief from cough, and an absence of excessive secretions at the end of life. Nurses must use all available resources to provide relief and optimize breathing status for patients with serious illness.

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CHAPTER 17

Bladder Management in Palliative Care

Naomi Farrington and Catherine Murphy

Key Points

- Urinary dysfunction in palliative care can cause great distress and discomfort for both patients and their caregivers. Nursing management of these issues is a priority for care and should be matched with the patient's own clinical situation and preferences.
- The causes of urinary dysfunction in the patient receiving palliative care are myriad, including the presence of a malignant tumor, iatrogenic factors, infection, neurological factors, or other comorbidities. Treatment or management strategies that reflect the etiology of the patient's condition should be considered, and this may include the selection of products or devices as well as pharmacological solutions or behavioral interventions.
- There is little robust evidence to support many aspects of nursing management of urinary issues in palliative care, including the insertion of indwelling urethral urinary catheters. As such, nurses are required to work in partnership with patients, families, and other members of the patient's healthcare team, bringing to bear their clinical and interpersonal skills in order to deliver high-quality care.

Introduction

Our overall goal as nurses caring for patients approaching the end of life must be to intervene to reduce distress and discomfort without causing further distress and discomfort. Management of urinary difficulties in palliative care should be as much a priority for nursing care as symptoms such as pain and nausea, as these, too, can cause great distress and discomfort.[1] The challenge is to manage the patient's bladder symptoms in a manner that pays attention to their medical situation (including proximity to death), emotional state, and personal preferences. As such, goals of care are likely to be different in each individual case, and management strategies must reflect this.

This chapter discusses the urinary and bladder difficulties that may occur in a patient approaching the end of life and the options for nursing care that can be considered, with personalized, holistic care in mind.

The urinary system can be divided into the upper urinary tract and the lower urinary tract (see Figures 17.1 and 17.2). The upper urinary tract comprises the kidneys and the ureters. The lower urinary tract comprises the bladder and the urethra. The kidneys are essential for maintaining water and electrolyte homeostasis within the body. They filter nearly 200 L of fluid from the body's bloodstream every day, which allows toxins, metabolic wastes, and excess ions to leave the body in the form of urine, while returning vital substances to the blood.[2] The two ureters transport the urine produced in the kidneys to the bladder, where it is stored temporarily before being carried through the urethra to the exterior of the body in the process of micturition or urination.

Factors affecting urination in a patient receiving palliative care include:

- *Pharmacological or treatment factors*: Medications such as sedatives or opioid analgesics may affect a patient's ability to recognize the need to void, or to access toileting facilities or products effectively. Diuretics may increase urine production, leading to urinary frequency. Oncological treatments including chemotherapy and radiotherapy can cause bladder irritation, bladder spasm, or hemorrhagic cystitis.
- *Urinary tract infection (UTI)*: UTI may cause urinary incontinence[3] (or exacerbate existing urinary incontinence), bladder irritation, and bladder spasm.
- *Restricted mobility*: Severe pain or dyspnea can impair a patient's ability to access toileting facilities or products in a timely fashion. In addition, the disease process itself can lead to weakness or exhaustion.
- *Cognitive impairment*: Chronic cognitive impairment such as dementia, or acute cognitive impairment such as delirium or confusion may mean that a patient is unable to recognize or respond to cues to urinate. Delirium is common in the last weeks or days of life and can be caused by metabolic disturbance, organ failure, certain drugs (including benzodiazepines and opioids), sepsis, hypoxia, and primary or secondary cerebral tumors.[4]
- *Constipation or stool impaction*: Constipation is common in the palliative patient due to factors including immobility, dehydration, metabolic factors, intestinal dysmotility, and opioid use.[5] Constipation can have a negative impact on urinary function as bladder and bowel function are intimately connected.[6]
- *Surgery*: Urethral surgery such as prostatectomy, or surgery which indirectly affects the urethra such as hysterectomy,[7,8] can lead to intrinsic sphincter deficiency and therefore urinary incontinence.
- *Neurological factors*: Whether associated with terminal disease itself or arising from existing long-term comorbid conditions,

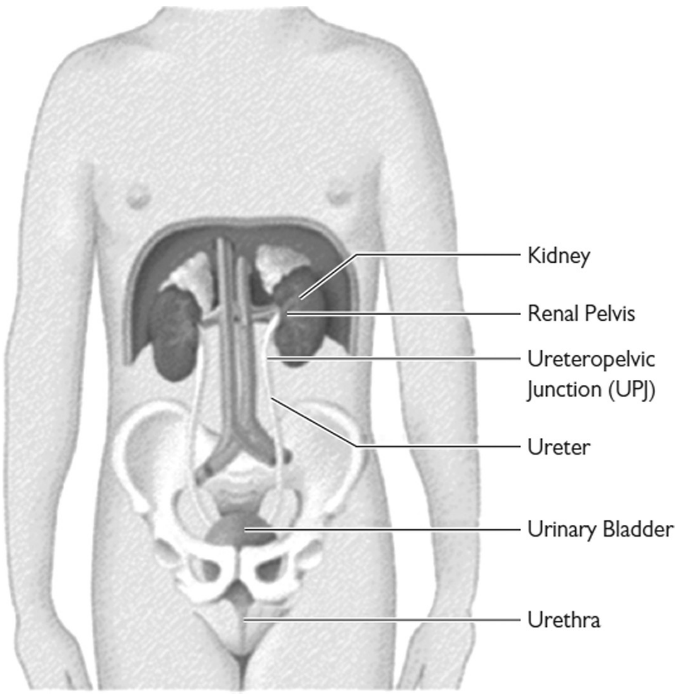

Figure 17.1 The female urinary tract.
Source: Ferrell BR. *Oxford Textbook of Palliative Nursing*. 4th ed. New York: Oxford University Press; 2015. Reprinted with permission.

neurological factors can significantly contribute to bladder dysfunction in the palliative patient, causing urinary incontinence, voiding difficulties, or urinary retention. In order for the bladder to enact its dual functions of storage and voiding effectively, the connections between the micturition center in the brain, the spinal cord, and peripheral nerves which enervate the bladder and sphincter must be intact. Disruption to these pathways leads to urological dysfunction. *Neurogenic bladder or neurogenic lower urinary tract dysfunction* (NLUTD) is the term often given to bladder dysfunction caused by neurological damage.[9]

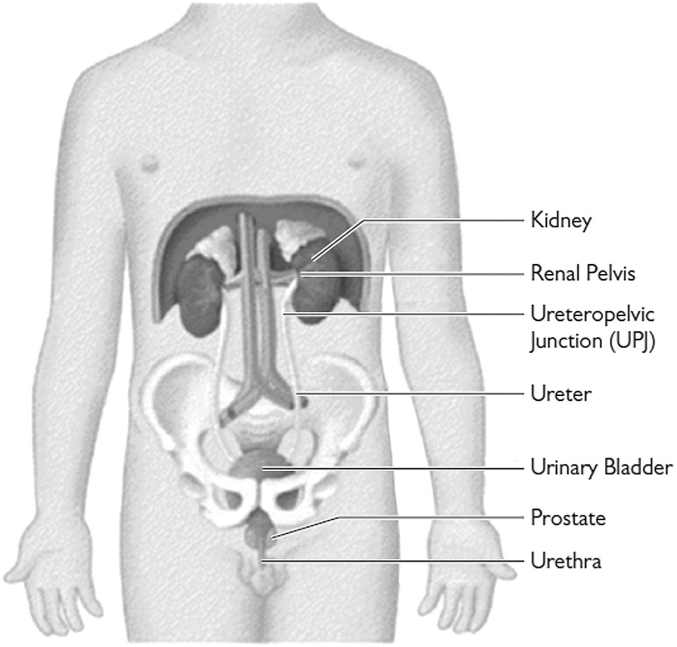

Figure 17.2 The male urinary tract
Source: Ferrell BR. *Oxford Textbook of Palliative Nursing*. 4th ed. New York: Oxford University Press; 2015. Reprinted with permission.

- *Presence of tumor*: In addition to neurological effects that can be caused by primary or secondary tumors in the brain or spinal column, bladder outlet obstruction can result when there is a carcinoma of the prostate or urethra or a pelvic tumor which causes urethral compression. Primary bladder tumors can cause inflammation of the bladder.

Many of the issues discussed in this chapter are not specific to palliative care, but the management strategies are specific in that they take into account goals of care and proximity to death.

Voiding Dysfunction

In the terminal phase of life, production of urine sometimes slows or ceases altogether.[10,11] This is an expected part of the dying process and is not usually cause for alarm. However, a reduction or cessation in urinary output prior to this phase can signal an underlying problem which merits attention and can potentially be reversed. Distinction must be made between lack of urine output caused by failure of the kidneys to filter blood and make urine (*anuria/oliguria*), blockage preventing flow of urine between the upper and lower urinary tracts (*urinary stasis*), and failure of the bladder to empty (*urinary retention*).[12]

Urinary retention is the inability to empty the bladder completely. It can be categorized by several factors: complete or partial emptying, acute or chronic duration, painful or not, by underlying cause (obstructive or nonobstructive), and as high- or low-pressure.[13] However, retention lacks a clear, widely accepted clinical definition, thus having the potential to lead to both under- and overtreatment. It is caused by one of two disorders: bladder outlet obstruction (in which flow from the urethra is obstructed) or deficient detrusor contraction strength (in which bladder muscle strength is insufficient to effectively empty the bladder),[12] detailed in Table 17.1.

Management will depend on the root cause; therefore, it is important that an accurate history is taken and examination (including using an ultrasound bladder scanner if available) is thorough. It is

Table 17.1 Causes of bladder outlet obstruction and deficient detrusor contraction strength in the patient receiving palliative care

Causes of bladder outlet obstruction	Malignant tumors of the prostate, urethra, or bladder (anatomic obstruction); Detrusor-sphincter dyssynergia (functional obstruction); Inflammation of the prostate, for example due to radiotherapy; Urethral stricture; Bladder calculi; Fecal impaction.
Causes of deficient detrusor contraction strength	Denervation caused by a neurological lesion; Radiation damage to the detrusor muscle itself; Decompensation of the detrusor muscle after a period of prolonged obstruction; Medication including opioids or antimuscarinics.[60]

important to distinguish between urinary retention and oliguria. If more than 400 mL is present in the bladder, retention is probable. In a dying patient who may be unable to communicate verbally, restlessness could signal urinary retention. Initially, conservative measures should be employed in an attempt to rectify urinary retention in the palliative patient, such as rectal emptying (most commonly by way of aperients rather than by more invasive methods like manual evacuation), or, for male patients, assistance to stand to void. In addition, pharmacological review to assess the need for drugs which have the potential to cause constipation or reduced detrusor activity should be conducted. If these measures are ineffective, an indwelling or intermittent urinary catheter may be employed if retention is confirmed by use of ultrasound bladder scanning. The choice between an intermittent and an indwelling urinary catheter will depend on the context of care, including the availability of a caregiver who can catheterize and the preferences of the patient.

Neurological lesions are caused by damage to nervous tissue as a result of injury or disease and can lead to voiding difficulties. The type of urological dysfunction that occurs depends on the location of the damage; for example, neurological lesions above the pontine micturition center in the brainstem (caused by presence of a posterior fossa tumor) can lead to voiding dysfunction, commonly urinary retention,[14] while a lesion that occurs below the pons in the spinal cord often leads to detrusor-sphincter dyssynergia (lack of coordination between bladder and sphincter) and therefore retention.[15]

Neurological lesions leading to bladder dysfunction can be caused by multiple factors including but not limited to:

- *Brain and brainstem*: Brain tumors, dementia, Parkinson's disease, cerebrovascular accident (CVA), or traumatic brain injury
- *Spinal cord*: Multiple sclerosis (MS), spina bifida, traumatic spinal cord injury, spinal surgery
- *Peripheral nervous system*: Diabetes, chronic alcohol abuse, chemotherapy-induced peripheral neuropathy, Guillain-Barré syndrome
- *Other*: HIV, systemic lupus erythematosus (SLE)[16]

In a patient undergoing palliation, it is unlikely that many of the usual investigations (such as urodynamic testing) or treatments (such as injection of botulism toxin, electrical nerve stimulation, or surgery) designed primarily for a nonpalliative population would be recommended. Conservative management is likely to be more appropriate. Depending upon the primary urological issue, this may include:

- Indwelling urethral or suprapubic catheter/intermittent catheterization[9]
- Continence products such as urinary sheaths[17]
- Anti-muscarinic therapy[18]
- Behavioral treatment
- Toileting assistance.

The benefits of these methods will need to be balanced with potential risks to the patient (e.g., urinary tract infection introduced by catheterization). Other options may be considered in discussions with the patient and his or her clinical team if survival for some months is expected or if the symptoms are severe and uncontrolled by conservative management.

Metastatic spinal cord compression (MSCC) is developed by about 5% of patients with cancer.[19] It is a medical emergency and often presents in the acute setting; however, by its very nature (metastatic cancer) it is a concern for palliative care nurses. It occurs when the spinal cord or cauda equina is compressed (e.g., by direct pressure of a tumor) in such a way that could cause neurological disability.[20] If diagnosis and treatment is delayed, the consequences can be serious, with irreversible loss of motor and bladder function.[21] Urinary incontinence is a late feature of spinal cord compression, but with cauda equina syndrome, bladder dysfunction in the form of retention or overflow incontinence may present at an earlier stage.[22] The following patient case study illustrates the potential management for a patient presenting with MSCC.

Case Study: A Patient with Advanced Prostate Cancer

Mr. Taylor is a 67-year-old man with advanced hormone-resistant prostate cancer. He has recently discontinued chemotherapy due to disease progression. He is admitted to the hospital from primary care with symptoms including bilateral sciatic pain and urinary retention. Due to the presence of known metastases, spinal cord compression is suspected. The following management strategies are employed following an urgent magnetic resonance imaging (MRI) scan confirming cauda equina syndrome:

- Administration of analgesia for comfort
- Flat bed rest with neutral spine alignment (venous thromboembolism prophylaxis and pressure area care is necessary)
- Bladder scan and indwelling urinary catheterization for relief of retention
- Administration of high-dose dexamethasone to relieve peri-tumoral edema
- Plan for surgical decompression of the spine followed by radiotherapy

This management plan is discussed with Mr. Taylor, his wife, and his two adult sons. Mr. Taylor understands the potential risks, but is reluctant to undergo surgery, and therefore radiotherapy with further high-dose steroids to combat radiation-induced edema is initiated. Following successful treatment, Mr. Taylor undergoes a trial removal of his indwelling urinary catheter. He successfully manages to pass urine and is discharged home with his wife and the support of the community palliative care nursing team.

Many patients like Mr. Taylor are catheterized due to urinary dysfunction. However, there is little research-based evidence to guide urinary catheter use at the end of life.[1] Despite this, a significant proportion of patients in receipt of palliative care in an acute or hospice setting are catheterized.[23,24] Insertion of a urinary catheter in the patient receiving palliative care must be carefully considered. Although insertion of the catheter may provide comfort from retention and keep an incontinent patient dry, the act of insertion itself may cause distress, and an indwelling catheter may be uncomfortable.[25] In addition, urinary catheters may present problems of their own, including leakage due to bypassing, blockage, and infection.[26–28] There are a number of reasons it is generally deemed appropriate to insert a urinary catheter at the end of life.

- Urinary retention/distended bladder
- Immobility due to severe pain (meaning that using a bedside commode is impossible and that frequent changes of bed linen caused by episodes of incontinence is distressing)
- Management or prevention of wound damage such as sacral pressure ulcers[29]

Urinary incontinence alone is not an indication for urinary catheterization. If an indwelling urethral catheter is inserted, daily assessment should be made as to whether the catheter is still required. Intermittent catheterization may be considered as an alternative to indwelling catheterization, depending on each patient's health condition, preferences, and life expectancy.

Incontinence and Toileting

Almost everyone will need help to manage toileting (intentional opening of bladder or bowels) or urinary incontinence (involuntary loss of urine) at the end of life. High rates of toileting problems and incontinence at the end of life are associated with functional and cognitive decline, often with additional impact from curative and palliative treatments. Prevalence varies by diagnosis and proximity to death, with sudden death associated with lowest rate (range 28.6–37.0%) and frailty or dementia the highest (65.3–72%) in the last year of life.[30–32] By the last month of life 67–89% of people in nursing homes were found to experience incontinence,[31] and in acute palliative care environments, incontinence increases in last 7 days of life (30% to 65%).[10] However, decreased urine output is associated with high likelihood of death within 3 days.[10]

As cognitive and functional abilities decline, the ability to self-manage toileting reduces and people become more reliant on caregivers to access toileting facilities (e.g., commodes or urinals) or voiding becomes involuntary and containment products are required. Generic assessment tools assessing a broad range of symptoms at the end of life do not include the detail required to fully assess incontinence, but currently no specific tool is available to guide end-of-life continence assessment.[33] However, everyone approaching the end of life should be assessed for current or potential incontinence or toileting problems, including:

- Identifying any potentially modifiable causes and precipitating or relieving factors
- Determining the frequency and severity of urinary leakage or toileting difficulties
- Establishing current containment methods used and their usefulness and exploring alternatives
- Evaluating the impact on the patient's quality of life, including a holistic assessment of the individual's experience of his or her symptoms
- Identifying changing needs and planning ahead[34]

Appropriateness of interventions to reduce either the frequency or severity of urinary leakage or the impact of the leakage needs to be judged in the context of proximity to death, as well as cognitive and physical limitations. In the terminal phase of life, there are two main bladder management goals: symptom management including avoidance of pain or discomfort and achieving social continence to protect personhood and dignity. There is no evidence to support or refute any of the commonly used pharmacological, lifestyle, or behavioral interventions aimed at the wider population or the frail elderly to achieve these goals in the last days and weeks of life.[34] Most commonly used interventions, such as dietary modifications or bladder training, are unlikely to be appropriate in the last weeks of life. For some people, behavioral interventions such as prompted voiding could support the maintenance of continence while physical and cognitive functionality allows.[34]

Where the trajectory of decline is clear, increasing reliance on caregivers and toileting or incontinence aids should be anticipated. As functional ability declines, patients will require increased support to reach and use toilets or toileting aids (such as commodes or urinals) or assistance with containment products such as absorbent pads or urinary sheaths. Indwelling urinary catheters are commonly used, and although guidelines widely accept symptom management at the end of life as a valid reason for using a catheter, uncertainty about best practice at the end of life remains.[1,34]

Choosing the right toileting aid or containment product can be complex. The individual's physical needs and personal preferences, daily activities, the context of care (e.g., who will be providing day-to-day care—family caregiver or healthcare professional) and the availability of devices will impact on decision-making. It can be necessary to trial several products to find the one that best meets an individual's needs, as illustrated by the following patient case study.

Case Study: A Patient with Incontinence

Mrs. Patel was 84 and lived in a nursing home. She recently fractured a hip, was very frail, and was believed to be in the last weeks of life. She had been unable to get out of bed to use a toilet or commode, she found bed pans painful to use due to the need to move her hips, and found absorbent insert pads often leaked, leading to uncomfortable changes of bed linen. After discussions on the risks and benefits of catheter use with her nurse, Mrs. Patel requested to try an indwelling device. Her catheter continuously drained into a urine collection bag which was emptied by her caregivers. However, after a few days, Mrs. Patel became agitated because the catheter was uncomfortable and she developed a urinary tract infection, requiring antibiotics. After further discussions with her nurse, Mrs. Patel asked for the catheter to be removed and to try absorbent pads again, but this time with a wrap-around diaper design. This design better contained her urine and allowed for less frequent and less complex changes.

As seen in Mrs. Patel's case, a choice of products can be helpful. Table 17.2 details some commonly used products.

All products can be potentially hazardous, and those at the end of life are vulnerable to adverse effects; for example, infection from catheters or urinary sheaths, leakage leading to uncomfortable changes of bed linen, or trauma to skin or tissue from body-worn devices. With all of these products, regular careful attention to hygiene and washing should be maintained to minimize harm to skin from the urine,[35] to help maintain comfort, and to avoid unpleasant smells.

Common Bladder Disorders and Emergencies

If the nursing goal of palliative care is to lessen the patient's distress without causing further distress, a key issue for discussion must be bladder discomfort. Bladder discomfort in patients approaching the end of life can arise from a number of sources.

Table 17.2 Toileting aids and containment products suitable for patients receiving palliative care

Toileting aids provide an alternative to the toilet for when a patient can voluntarily void urine	**Bedside commodes** can be used by patients who can safely transfer (with or without support) from bed to commode and back and maintain a seated position, but are unable to reach a conventional toilet. Different size designs, from paediatric to bariatric are available to accommodate different body frames. The commode should be emptied and cleaned after every use to avoid smell. As condition can change rapidly at the end of life, care should be taken to assess the patient's ability to transfer before each use. **Handheld urinals** are available in designs (reusable or disposable) suitable for either men or women and can be useful when mobility is limited. Products for women tend to have a flat end which can be put into position underneath the patient, whereas products for men ("bottles") generally have an aperture to accommodate the penis. Urinals can often be used in a supine or seated position and might help to maintain independence by reducing the need for a caregiver to help with mobility. Different designs are available to help with different limitations, for example poor grip. **Bedpans** are more commonly used when people wish to move their bowels but are unable to safely or comfortably transfer to a commode or conventional toilet. Bedpans can be uncomfortable and difficult to clean outside hospital environments, and, generally, handheld urinals are preferred for micturition, particularly for men. Some women might prefer a bedpan if handheld urinals do not work well for them.
Containment products are used when the patient cannot comfortably or reliably control voiding. Many people benefit from using a combination of products (e.g., different products for day and night).	**Absorbent products** are the most commonly used containment products to manage urinary incontinence and are available in a wide range of designs and styles, including disposable and washable. Pads should contain leakage and smell, be comfortable, discreet, and easily changed. To get the right pad, assessment must consider level (light, moderate, or heavy) and type of leakage (e.g., urinary only or urinary and fecal), whether the person can stand for product changes (e.g., avoid pull-ups if the person cannot stand), convenience (e.g., washables can work well for heavy leakage, but require washing and drying facilities), and individual preferences. Product design requirements are likely to change as functional abilities decline. **Male devices** include urinary sheaths (condom catheters) and body-worn urinals that are attached via tubing to urinary collection bags. Sheaths come in different sizes, styles, and materials (latex or silicone), and men should be carefully measured to ensure a good fit. A new sheath should be fitted at least daily after washing. For men with a retracted penis, an external device that fits to the glans is available. Body-worn urinals can offer an alternative if a sheath is not successful, but might not be suitable for men nursed in bed. The use of **indwelling catheters** is described elsewhere, and indications for use in the terminal phase include urine retention, skin protection, or patient preference for comfort (e.g., frequent product changes cause pain). However, it is important to remember that catheterization is an invasive procedure and alternatives should be fully explored.

Bladder spasm (sometimes discussed as *overactive bladder*) occurs when the detrusor muscle contracts suddenly. This can cause intense suprapubic and urethral pain. Spasms can also cause an urge to urinate and can force urine out of the bladder, leading to leakage. These spasms can therefore be very distressing for the patient. Common causes of bladder spasm include:

- *Disease-related*: Tumor infiltration, blood clots, spinal cord injury or other neurological conditions
- *Treatment-related*: Radiation fibrosis, chemotherapy- or radiation-induced cystitis, bladder or other lower abdominal surgery, medications such as intravesical bacillus Calmette-Guerin (BCG) or mitomycin (MM)
- *Mechanical causes*: Presence of indwelling catheter or ureteral stent
- *Infective causes*: Urinary-tract infection

Treatment for bladder spasm will depend on the cause and also the situation and preferences of the patient. If the cause is an indwelling catheter, the catheter could be changed, the volume of the balloon could be reduced, or a bladder washout could be performed to reverse catheter sludging, although there is not enough evidence of the efficacy of this technique to recommend a particular protocol.[36] If these are not sufficient, consideration should be made as to whether the catheter could be removed altogether or whether intermittent catheterization could be employed as an alternative. Pharmacological treatments can be employed to reduce bladder spasm or relieve the resulting pain. Antimuscarinic drugs such as oxybutynin or tolterodine reduce the sensitivity of the bladder muscle, decreasing bladder contractions.[37] Tricyclic antidepressants such as imipramine and amitriptyline may also help to reduce spasms.[38] Analgesics such as morphine can be used to reduce pain if it is severe. Antibiotics can be administered for urinary tract infection if it is believed that the patient's quality of life will be improved.[39] Overactive bladder in the absence of spasm or pain can be managed with the use of a condom catheter, adaptation of the home environment, and effective nursing support where pharmacological treatments cause significant side effects or are of no therapeutic benefit.[40]

Hemorrhagic cystitis occurs when the epithelium of the bladder is damaged, leading to lower urinary tract symptoms including bladder irritation, painful and/or frequent voiding, and hematuria. Oncology patients are at risk as the causes include chemotherapy (particularly cyclophosphamide and ifosfamide, which are excreted through the bladder) and pelvic radiation. Bone marrow transplant patients are at particular risk due to the high levels of chemotherapy drugs they receive as part of their treatment[41] and their consequent susceptibility to BK virus–associated hemorrhagic cystitis. Hemorrhagic cystitis may also be caused by infection. This is an important condition for both nurses and patients to recognize as consequences can be severe, including urinary outlet obstruction, anemia due to bleeding, or even urosepsis (a severe systemic infection). Management strategies involve removing the cause of the problem, for example cessation of chemotherapy (if chemotherapy is the cause), or administration of antibiotics (if infection is the cause). Comfort measures such as administration of analgesics may also be appropriate.

Treatment interventions for hemorrhagic cystitis can include:

- Administration of intravesical medications such as hyaluronic acid
- Administration of hyperbaric oxygen
- Surgical options, including cutaneous ureterostomy, cystoscopy and diathermy, vesical artery embolization, and supravesical urinary diversion[42]

With all of these treatments, their appropriateness for palliative patients must be assessed.

As always, prevention is better than cure. Aggressive intravenous hydration, the administration of mesna (2-mercaptoethane sodium sulphonate), and continuous bladder irrigation alongside cyclophosphamide or ifosfamide can reduce the risk of the patient developing hemorrhagic cystitis, although these are not universally effective.

Hematuria is the presence of blood in the urine. It can be caused by invasive tumors, clotting defects, urinary tract infection, urinary tract stones, or chemotherapy- or radiation-induced cystitis. Bleeding can be microscopic or gross. In palliative care, intervention is not necessarily required if there is microscopic hematuria or if gross hematuria does not lead to urinary outlet obstruction or a clinically significant reduction in hematocrit or hemoglobin. For gross hematuria requiring treatment, required nursing actions are as follows:

- Review medication to check whether the patient is taking anticoagulants or NSAIDS (these may need to be suspended)
- Urinalysis (dipstick and microscopy) to determine infection status and location of bleeding

If bleeding persists, cystoscopy may be considered, but this must be carefully balanced with the goals of care for patients with advanced illness. The same may be said for intravenous fluid infusion and transfusion of red blood cells. Catheterization with a large-gauge catheter (22–24 French) and irrigation may be necessary if gross bleeding results in clots and obstruction, and if the patient can tolerate the catheter in situ.[43]

UTIs are common at the end of life, with an increased prevalence associated with having an indwelling urinary catheter.[44] However, diagnosing a UTI is not always straightforward and distinguishing between UTI and an asymptomatic bacteriuria that does not require treatment can be problematic, particularly in older adults or those unable to report symptoms.[45] Consensus guidelines have developed UTI definitions that generally include a urine culture with 10^5 CFU/mL or higher combined with the presence of genitourinary symptoms (i.e., dysuria, suprapubic pain or tenderness, frequency or urgency of urination).[45] UTIs can cause significant discomfort and delirium for patients at the end of life and can lead to sepsis and unwanted admission into acute care,[46] so it is important that symptom burden is minimized. Treatment guidance recommends considering narrow-spectrum antibiotics such as trimethoprim or nitrofurantoin as first-line treatments. Broad-spectrum antibiotics (e.g., amoxicillin/clavulanate, quinolones, and cephalosporins) should be avoided as they increase the risk of *Clostridium difficile* infection, methicillin-resistant *Staphylococcus aureus* (MRSA), and resistant UTIs that are becoming increasingly problematic.[47] However, UTIs are also one of the most common reasons for using antimicrobials at the end of life,[45] and unnecessary use should be avoided due to the potential for unwanted side effects (e.g., nausea or allergic reaction) and the burden of antimicrobial resistance. Asymptomatic bacteriuria should not be treated with antibiotics.

Psychosocial Factors and Care Environment

As the end of life nears, the focus of care shifts from treatment to maintaining dignity and comfort. Taboos around both death and bladder care, particularly incontinence, continue and patients, caregivers, and many healthcare professionals can find the topic difficult to discuss. However, patients have identified loss of dignity as a major concern as they approach death,[48] and, to help protect dignity, nurses must not shy away from conversations on bladder management and the dying process. This is particularly important if people wish to die at home and informal caregivers will be involved in day-to-day care.

Little is known about patients' preferences for bladder management at the end of life. However, we do know that maintaining privacy during intimate care such as washing, toileting, catheterization, and bowel interventions is viewed as important to patients and their informal caregivers.[49] Additionally, many people wish to die at home,[50] but this can be prevented due to the lack of support available for activities such as bladder care in community settings, and, even in countries where palliative care provision is advanced, the lack of "dying out of hours" services leads to the burden of care falling to informal caregivers,[49,51] which can be problematic for both the patient and the caregiver. Some patients might worry about having intimate care provided by family members,[52] and needing help with managing bladder emptying can add to patients' fears at the end of life. Furthermore, coping with incontinence problems has been demonstrated to greatly add to distress and workload for caregivers[53,54] who report feeling unprepared and unsupported in their role[55] and have requested more practically focused help to avoid crises, including information and guidance.[56]

Particularly when informal caregivers are involved in day-to-day bladder care at the end of life, they should be provided with the information, support, and equipment to successfully undertake the role, including preparation for sudden deterioration to avoid crisis situations. However, caregivers are often reluctant to seek help for incontinence-related problems.[57] To help individuals and their caregivers to protect dignity, avoid chaos or exhaustion, and maintain social continence, healthcare professionals should be proactive in openly discussing bladder problems and management strategies.[58]

Proactive discussions with patients (where possible) and informal caregivers should include explaining the need for regular assessment to take into account changing circumstances, listening to patient preferences, establishing the context of care (e.g., who will be caring for the patient), and the likely trajectory of incontinence needs and potential interventions (e.g., provision of bedside commode or absorbent products) that might be beneficial. Different palliative trajectories, such as short illness with rapid decline or long illness with intermittent acute episodes have been identified[59] and might impact on the nature of incontinence symptoms encountered and the speed of adaptation required. It is likely that, particularly when the person declines quickly, the need for rapid adaptation will increase the level of support and information required.

Conclusion

Bladder management in a patient receiving palliative care, whether in a hospital, hospice, or home environment, is a complex issue. It is, however, one which nurses and other healthcare professionals must be prepared to address, especially as doing so and finding a solution to a problem that has been perceived as intractable can make a tangible difference to the daily lives of both patients and caregivers. Nurses involved with looking after patients with bladder difficulties nearing the end of life may face barriers including lack of resources or knowledge about products available to assist these patients as well as the psychological and clinical considerations described in this chapter. Knowledge of local policies, procedures, and guidelines is therefore essential, in addition to the general overview provided by this chapter.

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CHAPTER 18

Lymphedema Management

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Key Points

- Lymphedema is a syndrome of abnormal accumulation of lymph fluid and multiple symptoms that is caused by irreversible damage to and congenital malformation of the lymphatic system.
- There is no cure for lymphedema, and management of lymphedema requires daily self-care and changes in lifestyle.
- Promotion of lymph fluid flow and prevention of infection is fundamental to achieve long-term effective lymphedema management.

Definitions

Lymphedema is the pathological accumulation of protein-rich lymph fluid in the interstitial tissue spaces due to an imbalance between lymph fluid production and transport, manifested clinically by tissue swelling and other physical symptoms (e.g., pain, heaviness, tightness, tingling).[1–3] *Edema*, a symptom, refers to excessive accumulation of fluid within interstitial tissues and is one of the manifestations of lymphedema. Long-term, neglected edema, such as lower extremity venous insufficiency, can develop into chronic lymphedema. Discerning the difference between edema and lymphedema ensures appropriate treatment.

One or several factors can precipitate an imbalance in extracellular fluid volume. Excess fluids, proteins, immunological cells, and debris in affected tissues can produce chronic inflammation and connective tissue proliferation, including hypertrophy of adipose tissue.[1,3,4] Some degree of progression usually occurs and can produce subcutaneous and dermal thickening and fibrosis.[2] Lymphedema and edema are contrasted in Table 18.1, which provides definitions, signs and symptoms, and basic pathophysiology.[3,4]

Prevalence and Risk Factors

The world prevalence of edema is unknown and that of lymphedema is poorly documented. Primary lymphedema, a genetic disorder, is attributed to embryonic developmental abnormalities, which may be sporadic or part of a syndrome caused by either chromosomal abnormalities (e.g., Turner's syndrome) or inherited single-gene defects.[5,6] Primary lymphedema occurs in about 1 in 6,000 individuals and is more common in women than men, with a 3:1 ratio.[7]

Secondary (acquired) lymphedema results from obstruction or obliteration of lymph nodes or lymphatic vessels.[1,8–10] Cancer, trauma, surgery, severe infections, cardiac disease, poor venous function, immobility, or paralyzing diseases are major causes of secondary lymphedema.[1,8–10] In developing countries, lymphatic filariasis, a parasitic infection transmitted by mosquitoes, is the predominant cause of secondary lymphedema. Mosquitoes transmit filariasis nematodes, which embed in human lymphatics and release inflammatory substances that cause progressive lymphatic damage. It is estimated that the worldwide incidence of filariasis is 856 million.[11] In developed countries, the most common causes of lymphedema are cancer and/or its treatment (e.g., surgery and radiation therapy) that damages the lymphatic system and surrounding soft tissues, resulting in the inability of the lymphatic system to transport lymph fluid from the tissues to the blood vascular system.[8–10] As a chronic and progressive disease, lymphedema is a significant health issue for many cancer survivors, including people with breast cancer (20–40%), gynecologic cancer (20%), melanoma (16%), genitourinary cancer (10%), head and neck cancer, and sarcoma (4%)[12,13] Risk factors related to cancer treatment include extent of surgery, extent of lymph node resection, and radiation therapy.[14–17]

Other major factors of lymphedema risk include inflammation, infection, and higher body mass index (BMI).[2,10,14] Breast cancer survivors who undergo surgery and dissection of lymph nodes and vessels are known to have a compromised lymphatic system, which makes them more vulnerable to infection and impaired lymphatic drainage.[2,10,15] Women who had previous infections were more likely to develop lymphedema; weight gain and obesity (BMI >30 kg/m^2) increase lymphedema risk.[10,14–16] Nevertheless, these risk factors only partially explain who develops lymphedema. Lymphedema can and does occur in women lacking these risk factors. Research on the effect of genetics or genetic variations on secondary lymphedema related to cancer treatment is very limited. However, mutations and genetic variations in lymphatic-specific growth factors are associated with hereditary lymphedema and secondary lymphedema related to breast cancer, such as vascular endothelial growth factor (VEGF-C, VEGF-D, VEGFR2, VEGFR3) and inflammatory cytokines (interleukin [IL]-4 and IL-13).[15,17,18] Understanding the biological mechanism of lymphedema through the exploration of inherited genetic susceptibility is essential for finding a cure.

Table 18.1 Comparison of edema and lymphedema

	Edema	**Lymphedema**
Disorder	A symptom of various disorders	A chronic, currently incurable edema
Definition	Swelling caused by the excessive fluid in interstitial tissues—due to imbalance between capillary filtration and lymph drainage over time	Swelling (edema) caused by accumulation of lymph fluid within interstitial tissues as a result of lymphatic drainage failure, increased production of lymph fluid over time, or both
Signs and symptoms	Swelling, decreased skin mobility	Swelling, decreased skin mobility
	Tightness, tingling, or bursting	Tightness, heaviness, firmness, tingling, feeling of fullness, or bursting sensations
	Decreased strength and mobility	Decreased strength and mobility
	Discomfort (aching to severe pain)	Discomfort (aching, soreness to severe pain)
	Possible skin color change	Progressive skin changes (color, texture, tone, temperature), impairment in integrity such as blisters, weeping (lymphorrhea), hyperkeratosis, warts, papillomatosis, and elephantiasis
	Pitting scale is often used:	*Pitting scale is NOT used.*
	1+ Edema barely detectable	
	2+ Slight indentation with depression	
	3+ Deep indentation for 5–30 s with pressure	
	4+ Area 1.5–2 times greater than normal	
Pathophysiology	Capillary filtration rate exceeds fluid transport capacity	Inadequate lymph transport capacity
		Primary—Inadequately developed lymphatic pathways
	Example: Heart failure, fluid overload, and/or venous thrombosis are common causes of increased capillary pressure, leading to an increased capillary filtration rate that causes edema	*Secondary*—Damage outside lymphatic pathways (obstruction/obliteration)
		Initial sequelae of transport failure:
		Lymphatic stasis → Increased tissue fluid → Accumulated protein and cellular metabolites →lymphedema
	Note: Timely treatment of the underlying cause or causes usually reduces edema	Further increased tissue water and pressure
		Potential long-term sequelae:
	Prolonged, untreated edema can transition to lymphedema	Macrophages seek to decrease inflammation
		Increased fibroblasts and keratinocytes cause chronic inflammation
		Gradual increase in adipose tissue
		Lymphorrhea (leakage of lymph through skin)
		Gradual skin and tissue thickening and hardening progressing to hyperkeratosis, papillomatosis, and other problems
		Ever-increasing risk of infection and other complications

Source: References 8, 9, 10, and 24.

Impact

Lymphedema impacts an individual's quality of life (QOL), causing physical discomfort, functional disabilities, impaired occupational roles, poor self-image, decreased self-esteem, interrupted interpersonal relationships, financial burden, and lifestyle changes.[19,20] Physically, lymphedema leads to distressing symptoms such as swelling, firmness, tightness, heaviness, pain, fatigue, numbness, and impaired limb mobility.[8,9,16] In addition, lymphedema predisposes individuals to skin and tissue fibrosis, cellulitis, infections, lymphadenitis, and septicemia.[10,16,20] Prolonged fluid stasis can lead to severe skin and tissue symptoms, sometimes referred to as *elephantiasis*. Symptoms include hyperkeratosis (hard, reptile-like skin), warts, and papillomas (engorged and raised lymph vessels on the skin surface).[10,16] Chronic lymphedema, over a number of years, has also been associated with the development of the rare, usually fatal cancer, lymphangiosarcoma.[2] Functionally, lymphedema makes it difficult for individuals to accomplish tasks and impairs their abilities to fulfill work that involves heavy lifting, gripping, holding, fine motor dexterity, and repetitive movement of the affected limb.[20,21] Psychologically, individuals feel stigmatized and some experience loss of sexual attractiveness because of obvious disfigurement, which often elicits emotional distress, social anxiety, depression, and disruption of interpersonal relationships.[19,21] Routine check-ups for lymphedema management, long-term physical therapy, management equipment (compression garments, bandages, special lotions), and repeated cellulitis, infections, and lymphangitis create financial and economic burdens not only for survivors but also for the healthcare system.[22]

Anatomy, Physiology, and Pathophysiology

Edema

Edema is a symptom that results from an imbalance between capillary filtration and lymph drainage. Edema requires treatment of the underlying disorder that is precipitating tissue fluid excess. Precipitators can include cardiac, hepatic, renal, allergic, or hypoproteinemic disease; venous obstruction; and medication complications[23] (see Table 18.1). Chronic edema can develop into secondary lymphedema with sufficient lymphatic damage, such as in chronic venous insufficiency, posttraumatic swelling from significant soft tissue injury, or fractures of the lower extremities.[24]

Lymphedema

A healthy lymphatic system helps regulate the tissue cellular environment, including collecting and returning plasma and proteins.[25,26] Daily, 20–50% of the total accumulating plasma proteins travel through 2–4 L of lymph fluid in a healthy lymphatic system.[25,26] Lymphatics also remove cellular waste products, mutants, and debris; eliminate non–self-antigens; and regulate local immune defense in the process of maintaining homeostasis.[25,26] Unidirectional vessels traverse from superficial to deep lymphatics through 600–700 lymph nodes, carrying lymph fluid to the venous system at the right or left venous angle of the anterior chest on either side of the neck. Lymph nodes filter, concentrate, and purify lymph fluid, eliminating defective cells, toxins, and bacteria, explaining the increased risk of infection for patients with compromised lymphatics.[25,26] Lymphedema pathology signifies malfunction in any part of the process of collecting, transporting, filtering, and depositing lymph into the venous system. Lymphedema pathophysiology suggests disruption of these processes and is described in Table 18.1.

In brief, lymph fluid is transported initially from the interstitium by the initial lymphatic vessels, moving proximally through progressively larger collecting lymph vessels, filtered through lymph nodes, then drained into the two large lymph-collecting ducts, and finally returned to the venous bloodstreams via the left and right subclavian veins. Damage to any structures of the lymphatic system can lead to accumulation of lymph fluid in the affected area. Furthermore, physiological variations in each individual's lymphatic system, such as numbers or sizes of lymph nodes, make it difficult to quantify each individual's risk for lymphedema.

Secondary lymphedema from cancer treatment is caused by trauma to the lymphatic system mainly from surgery and radiotherapy.[8,11] Surgery creates disruption to the lymphatic system by directly dissecting lymph vessels and removing lymph nodes.[9] Unfortunately, lymph nodes do not regenerate once dissected.[25,26] Formation of scar tissue and tissue fibrosis from surgery create further impairment to lymph flow. The disruption or blockage of the lymphatic system reduces its ability to transport and filter the lymph, resulting in a functional overload and insufficient capability of the lymphatic system to transport the normal volume of lymph.[27] As a result, an abnormal accumulation of lymph fluid occurs, which leads to the swelling of the affected area.

Radiation exposure during radiotherapy is also traumatic to the lymphatic system. Radiation impairs the lymphatic system by causing tissue fibrosis surrounding the lymphatic vessels,[9] and it reduces lymphatic transport reserve by increasing long-term changes in basal lymph circulation and lymph flow in the affected area.[9,26] While lymphatic vessels are relatively insensitive to radiotherapy, lymph nodes are radiosensitive to conventional doses of radiotherapy.[26,27] The radiated lymph nodes respond first with lymphocyte depletion, followed by fatty replacement, then by fibrosis.[26,27] As a result, radiation hinders lymph nodes from properly filtering and transporting lymph and alters immune function. Research has not clarified the specific roles of chemotherapy in contributing to lymphedema. In addition to the definite risk from cancer treatment, certain personal risk factors such as weight gain or obesity (BMI >30), infection, and immobility increase an individual's risk for lymphedema.[8,9,14] Please check the mHealth System: http://optimallymph.org/ for the Lymphatic System video.

Precision Assessment and Diagnosis

Assessing and diagnosing lymphedema remains a challenge for research and clinical practice. Several factors contribute to the challenge: lack of universally recognized diagnostic criteria, failure to precisely evaluate symptoms, coexisting conditions, and lack of awareness of lymphedema among healthcare professionals.[15,27,28] Inconsistency in the criteria defining lymphedema and the use of different measures in research have presented tremendous challenges in the assessment and diagnosing of lymphedema.[3,9,15,28] Often, lymphedema is diagnosed via provider observation of swelling in clinical practice. Lymphedema can occur in the head, neck, shoulder, breast and thoracic regions, abdomen, lower extremities, foot, or ankle. No epidemiological studies have explored the incidence of lymphedema in these difficult-to-measure body areas, mainly due to lack of instruments to quantify swelling. As a result, precision assessment of lymphedema phenotype remains an ongoing challenge in research and clinical practice.[3,9,15,28] A critical need exists to understand heterogeneity (i.e., different types) of lymphedema phenotype to advance precision phenotype assessment of lymphedema and provide insights to biological mechanisms.

To optimize the precision assessment of heterogeneity of lymphedema phenotypes and ensure accurate diagnosis, it is important to conduct a careful review of the patient's health history to rule out other medical conditions that may cause similar symptoms, such as recurrent cancer, deep vein thrombosis, chronic venous insufficiency, diabetes, hypertension, and cardiac, hepatic, thyroid, and renal diseases. These alternative diagnoses should be ruled out before establishing a diagnosis of lymphedema and referring the patient for lymphedema therapy. "Best practice"[9–28] components of lymphedema nursing

Box 18.1 Sequential Components of Lymphedema Assessment

- *Rule out or address immediate complications* (i.e., infection, thrombosis, severe pain, new or recurrent cancer, significant nonrelated disorders)
- *History and physical examination*
  - Routine physical assessments: Vital signs, blood pressure, height and weight, body mass index
  - Past and current health status, including medications and allergies (especially antibiotic allergies and history of infection, trauma, or surgery in affected area)
  - Current activities of daily living (job, home responsibilities, leisure activities, sleep position, activities that aggravate lymphedema)
  - Current psychological health, support people, view of lymphedema and health
  - History of lymphedema etiology, presentation, duration, and progression
- *Patient knowledge of and response to lymphedema, interest in assistance and goals*
- *Third-party payer status*
- *Quantification of lymphedema status* (lymphedema signs and symptoms, volume, pain and other neurological symptoms, tissue status, range of motion of nearby joints, site-specific and overall patient function)

assessment are displayed in Box 18.1. The first assessment priority is proper diagnosis. For example, the assessment of a frail elderly woman with suspected lymphedema reveals that early symptoms of congestive heart failure are responsible for a suspected lymphedema. When the results of the physical assessment and patient history are combined with dialogue, the patient reports that she has replaced her cardiac medication with several natural supplements in order to save money and avoid "toxic drugs." Her edema resolves within several days after she resumes her cardiac medications. Some patients, especially those who are elderly, chronically ill, or significantly distressed, are not able to provide an accurate medical history. Reviewing the medical record can provide excellent assessment information. However, even the best medical record isn't always complete.

Supportive communication with the patient can encourage them to be open and not afraid to "admit" to deviations from their recommended treatment/medication regimens, which helps the clinician to accurately assess the patient's condition and response to treatment. Supportive communication helps to understand patient's perspectives and gain essential information, including the patient's (1) view of lymphedema, (2) readiness for instruction and treatment, (3) pertinent work and lifestyle, (4) spiritual concerns, (5) illness and adjustment issues, and (6) desired goals. Often the patient's initial goal is cure, which is unattainable. In this situation, the patient needs time to understand the chronicity of lymphedema and to formulate new goals. Nurses' awareness of patient quality-of-life goals fosters collaboration and management success. Instruction, support, multidisciplinary referrals, goal setting, assistance with self-care, complication avoidance, and long-term management are improved by nurses' and healthcare providers' understanding of patients' perspectives and knowledge.[29]

An early lymphedema diagnosis is often determined solely from a history and physical examination,[28] especially if conservative management is planned and symptoms are not severe. Questionable clinical symptoms or etiology may require further evaluation. Lymphoscintigraphy (isotope lymphography) can ensure definite lymphedema diagnosis.[9] Lymphography (direct) is now rarely used in lymphedema patients because of its potential to cause lymphatic injury and its inability to clarify function.[9]

Assessment for infection, thrombosis, or cancer metastasis is required at every patient contact.[9,16] Although later signs of infection or thrombosis are well known, awareness and careful assessment allow early diagnosis and treatment. Lymphedema progression or treatment resistance may be the earliest sign of complication or may represent a lack of response to current treatment. Changes in pain or comfort, skin (color, temperature, condition), or mobility and range of motion are other possible early signs of major complications.[3] Most infections develop subcutaneously, beneath intact skin. Cultures are not recommended because they rarely document a bacterial source and can further increase the risk of infection.[9] Suspected thrombosis or new or recurring cancer requires appropriate diagnostic evaluation (e.g., Doppler ultrasonography, magnetic resonance imaging, positron emission tomography, computed tomographic scanning). Venous ultrasonography is reported to be safer than venography for evaluation of suspected thrombosis in a limb with or at high risk for lymphedema.[9,26]

Basic treatment of complications are also included. Signs and symptoms of metastasis can include pain, neuropathies, new masses or lesions, skin/tissue color and texture changes, and treatment-resistant rashes. For thrombosis, signs can include distended veins, venous telangiectasia, and rapid edema progression beyond the affected limb into adjacent areas of the torso. Thrombosis requires anticoagulation, pain control, rest, and avoidance of use of external compression. Currently, no research clarifies the appropriate timing for use of compression after thrombosis, and the traditional 6-month delay until use of compression should be assumed. Discussion of this issue with the physician is appropriate. In contrast, some physicians recommend the use of limb support for several days or longer after painful thrombosis-related swelling, especially in the presence of metastatic cancer. Some clinicians suggest that compression can be safely applied post acute central venous thrombosis (CVT) and can ameliorate the exacerbation of swelling and other symptoms that occur in postthrombotic syndrome. Until research enables a practice standard, the timing of support and compression is based on clinician preference.

Case Study: A Patient with Thrombosis and Lymphedema

A diagnosis of early thrombosis was made for a 67-year-old patient with advanced metastatic lymphoma and leukemia when left leg thrombosis developed rapidly while the patient was hospitalized for a cancer complication. Thrombosis encompassed the entire leg. During anticoagulation, leg edema, pain, and signs of venous insufficiency continued to progress. Several weeks later, the patient was referred to the clinical nurse specialist for assistance. Excess edema volume in the affected leg (compared with the unaffected leg) was 94% (4,816 mL). A compression garment (similar to those elastic garments used after cosmetic surgery) was provided (with physician approval) for 1 week, and 9% limb reduction was achieved. Good product tolerance was reported. A demonstration of compression legging (lower extremity, full-leg product that uses high-low foam and a Spandex compression sleeve) was then provided with instructions to use it as tolerated, reverting to the compression garment whenever the compression legging was removed. One week later, follow-up assessment revealed edema reduction of 43%, compared with the initial volume. Excess volume had decreased from 94% to 54% (2,730 mL). The patient also agreed to referral to a lymphedema therapist to obtain daytime compression stockings and to undergo several sessions of lymphatic drainage massage. Five weeks after the initial assessment, the patient returned for follow-up wearing her new stockings, her "tight-legged" slacks, her wig, and a large smile. Pain level, skin color and condition, gait, and range of motion of the ankle, knee, and hip were significantly improved. Edema reduction in the lymphedema limb was 81%; excess volume was 18% (926 mL). By 4.5 months following the initial assessment, edema reduction had continued. Treatment included daytime stockings and compression legging usage several nights a week. Edema reduction at this time was 87%. Excess limb volume, compared to the contralateral leg, was 12% (634 mL).

Assessment of Symptoms

Lymphedema is a sign of an impaired lymphatic system.[1,2,9,26] Impairment in the lymphatic system leads to a chronic disease state with multiple associated symptoms, such as heaviness, tightness, firmness, pain, numbness, or impaired mobility.[3,10,15,16] The experience of lymphedema symptoms is an ongoing debilitating complication that impacts QOL.[20–22] Symptom assessment is essential since very often observable swelling and measurable volume changes are absent during the initial development of lymphedema.[3,10,15] Table 18.2 presents an example of a symptom checklist for breast cancer–related lymphedema.[4] Assessing lymphedema symptoms plays an important role in diagnosis until objective measurements capable of detecting latent stage of lymphedema are established in at-risk individuals.[26] Recent research shows that limb volume change (LVC) has significantly increased as breast cancer survivors' reports of swelling, heaviness, tenderness, firmness, tightness, and aching have increased.[3,30] In addition, a diagnostic cutoff of three symptoms was able to detect breast cancer survivors with lymphedema from healthy women with 94% of accuracy, while a diagnostic cutoff of nine symptoms identified survivors with lymphedema with 64% of accuracy. As early intervention leads to better clinical outcomes, patients with nine or more symptoms should be evaluated immediately and treated in a timely manner.[3] Recent research also examined if symptom clusters, denoted as groups of more than two symptoms, indicate different biological mechanism.[15] Three major symptom cluster phenotypes were identified: fluid accumulation, impaired limb mobility, and discomfort. The identification of different symptom cluster phenotypes provides a foundation for future research to explore the biological mechanism, so that targeted precision intervention for each symptom cluster phenotype can be developed to achieve optimal symptom management.

Table 18.2 Example of symptom checklist: breast cancer and lymphedema symptom experience index

The following questions are about symptoms in your affected arm, hand, breast, axilla (under arm), or chest today or in the past month.
Have you had ____? No Yes
1. Limited shoulder movement
2. Limited elbow movement
3. Limited wrist movement
4. Limited fingers movement
5. Limited arm movement
6. Hand or arm swelling
7. Breast swelling
8. Chest wall swelling
9. Firmness
10. Tightness
11. Heaviness
12. Toughness or thickness of skin
13. Stiffness
14. Tenderness
15. Hotness/increased temperature
16. Redness
17. Blistering
18. Pain/aching/soreness
19. Numbness
20. Burning
21. Stabbing
22. Tingling (pins and needles)
23. Arm or hand fatigue
24. Arm or hand weakness

Source: Copyright 2006. Rory Meyers College of Nursing, New York University. Contact Mei R. Fu, PhD, RN, FAAN; Telephone: 212-998-5314; e-mail: mf67@nyu.edu.

Quantification of Lymphedema

A variety of measurement approaches make quantification of lymphedema a problem.[15,28,31] Methods of measuring limb volume or circumference include sequential circumference limb measurement, water displacement, and infrared perometry.[31] Bioelectrical impedance is emerging as a possible alternative.[28] Unfortunately, lymphedema can also occur in the face, neck, shoulder, breast, abdomen, thoracic regions, and genital areas, which presents a challenge for quantification.[3,15,32]

Sequential Circumferential Arm Measurements

Measuring limb volume and circumference are the most widely used diagnostic methods. A flexible nonstretch tape measure for circumferences is usually used to assure consistent tension over soft tissue, muscle, and bony prominences.[28,31] Measurements are done on both affected and nonaffected limbs at the hand proximal to the metacarpals, wrist, and then every 4 cm from the wrist to axilla. Limb size and limb volume are calculated based on sequential circumferential arm measurements. The formula often used for calculating limb volume with a presurgery baseline limb volume is: Limb Volume Increase = (Affected Frustum Limb Volume$_{\text{Follow-up}}$ /Affected Frustum Limb Volume$_{\text{baseline}}$)/ (Contralateral Frustum Limb Volume$_{\text{Follow-up}}$ /Contralateral Frustum Limb Volume$_{\text{baseline}}$).[28,31] If presurgical baseline limb volume is not available, the following formula can be used: Limb Volume Ratio = Affected Frustum Limb Volume/Contralateral Frustum Limb Volume; Limb Volume–Difference = Affected Frustum Limb Volume–Contralateral Frustum Limb Volume.[28,31] Arm lymphedema is often arbitrarily defined as 2 cm or more in limb girth or 200 mL or greater difference in limb volume as compared to the unaffected limb or 10% volume increase in the affected limb from presurgery baseline limb volume.[28,31] Recent research has shown that among breast cancer survivors, a 5% or greater limb volume increase from presurgical baseline enables detectable differences in QOL and better clinical outcomes with interventions to promote lymph flow[30] (Figure 18.1).

Water Displacement

Although water displacement has been considered the "gold standard" for limb volume measurement and is identified as a sensitive and accurate measure in the laboratory setting, water displacement is seldom used in clinical settings because of spillover and hygienic concerns.[28] Patients submerge the affected arm in a container filled with water and the overflow of water is caught in another container and weighed. This method does not provide data about localization of the edema or shape of the extremity.[28] The method is contraindicated in patients with open skin lesions. Patients may find it difficult to hold the position for the time needed for the tank overflow to drain.

Infrared Perometry

The infrared perometer, an optoelectronic device developed to meet the need for a quick, hygienic, and accurate method for volume calculation, works similarly to computer-assisted tomography, but makes use of light instead of x-rays (Figure 18.2).[31,33] The perometer maps a three-dimensional graph of the affected and unaffected extremities using numerous rectilinear light beams and interfaces with a computer for data analysis and storage. A three-dimensional limb image is generated, and limb volume is calculated automatically. This optoelectronic method has a standard deviation of 8.9 mL (arm), less than 0.5% of limb volume with repeated measuring.[30,31] Perometer can be operated by nurses or lymphedema therapists after training.

Bioelectrical Impedance Analysis

Bioelectrical impedance analysis (BIA) measures impedance or resistance of the extracellular fluid using low frequency electrical current.[34] BIA provides an impedance ratio to calculate a Lymphedema Index (L-Dex ratio). With the development of lymphedema, the limb impedance decreases and the L-Dex ratio therefore increases. The L-Dex ratio ranges from −10 to +10. Since approximately 20% of true arm lymphedema cases are still missed by BIA with a cutoff point of greater than +7.1, it is critical for healthcare professionals to incorporate other assessment methods, including self-report, clinical observation, or perometry to ensure precision assessment of arm lymphedema[34] (Figure 18.3).

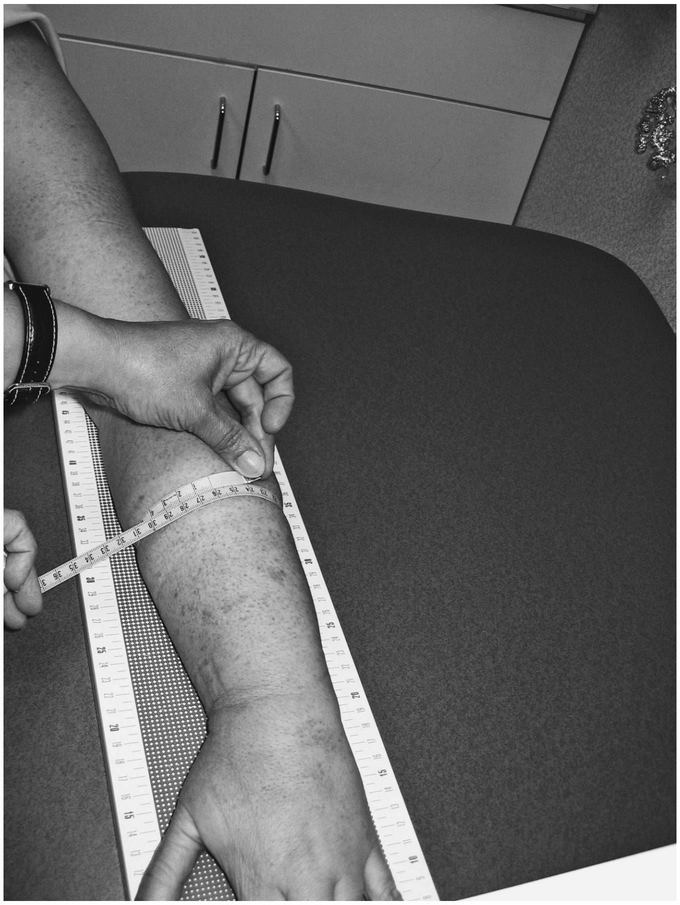

Figure 18.1 Tape measurement.

Lymphedema Risk Reduction

Patient education focusing on risk-reduction strategies holds great promise for reducing the risk of lymphedema. A recent systematic review based on findings from several randomized clinical trials (RCTs) from 2009 to 2014 have suggested that prevention and early intervention protocols focusing on the implementation of prophylactic patient assessment/monitoring and relevant interventions are effective to reduce risk of arm volume increase and to identify early stages of lymphedema development.[8] A recent one-group trial (N = 140) was completed with 4% attrition rate.[30] All the participants received face-to-face, nurse delivered *The-Optimal-Lymph-Flow* intervention to promote lymph flow and healthy weight. During the study period, two patients with sentinel lymph node biopsy and two patients with the axillary lymph node dissection had measurable lymphedema (>5% limb volume). At 12-month follow-up, among the four patients with measurable lymphedema, two patients' limb volume returned to preoperative levels without compression therapy but by maintaining *daily lymphatic* exercise. At 4–8 weeks after breast cancer surgery, 100% of participants reported at least one symptom (average seven symptoms); at 12 months after surgery, 65% participants were symptom free and the other 35% participants had an average of two symptoms. Furthermore, *The-Optimal-Lymph-Flow* has been developed as a digital therapy that uses behavioral and lifestyle changes to treat or manage health conditions, such as treating chronic pain or symptoms or optimizing management of

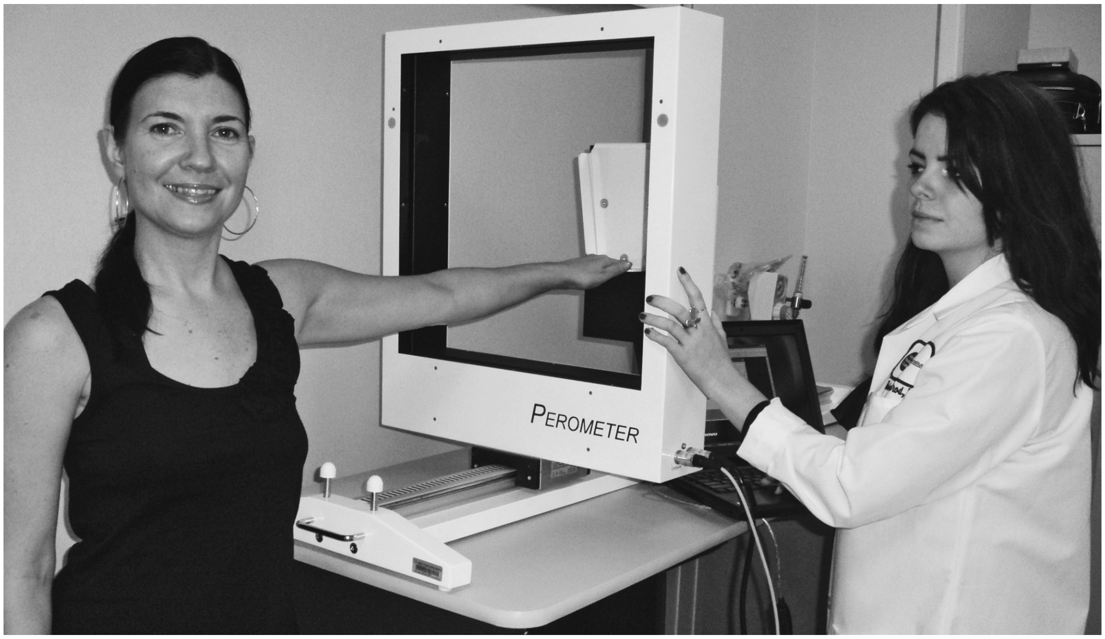

Figure 18.2 Infrared perometer measurement.

chronic illness or reducing the risk of lymphedema by utilizing web- and mobile-based digital technology to deliver treatment and monitor progress.[35,36] *The-Optimal-Lymph-Flow* mHealth system is a patient-centered, web- and mobile-based digital therapy focusing on safe, innovative, and pragmatic electronic assessment and behavioral strategies for lymphedema symptom management. Preliminary findings from the pilot research is promising.

Infection prevention is vital for lymphedema risk reduction.[30,35,36] Infection is a significant risk factor and is the most frequent lymphedema complication.[10,16,37] Risk increases with breaches in skin integrity. Occasional drawing of blood from the limb at risk is necessary for some patients when no other reasonable option exists.[8] Patients can request an experienced phlebotomist and emphasize their increased infection risk. Subcutaneous, intramuscular, or intravenous injections in the limb at risk can cause an allergic or inflammatory response and/or infection that may compromise a weakened lymphatic system. These risks must be compared with the benefit and risk of use of a central venous catheter or suboptimal venipuncture site such as the lower extremity.[8] Diabetes potentially increases breast cancer patients' lymphedema risk when the affected limb is used for continual blood sticks or insulin injections. Patients with bilateral limb risk, especially of the upper extremities, face lifelong decisions regarding adherence to precautions.

Breast cancer disease and treatment factors are associated with increased lymphedema risk, including advanced cancer stage at diagnosis and radiation therapy to the axilla or supraclavicular area after a mastectomy. The benefits of early nursing intervention in decreasing lymphedema occurrence, severity of secondary lymphedema, and lymphedema symptoms in breast cancer survivors have been well documented.[30,35,36] Nurses can assist high-risk patients by presenting or reinforcing prevention information and encouraging use of a well-fitted compression sleeve and gauntlet or glove at the earliest sign of edema. Emphasis on self-protection rather than rigid rules fosters patient empowerment.[30,35,36] For example, an empowered patient assumes responsibility for reminding staff to avoid use of the affected arm rather than expecting medical personnel to remember to do so.

In the past, breast cancer survivors were cautioned to restrict exercise as a way to reduce their risk for lymphedema. However, a growing body of evidence suggests that exercise does not necessarily increase lymphedema risk.[8] Research suggests that breast cancer survivors should be encouraged to carry out all postoperative exercises, resume normal precancer activities as tolerated, and be as fit as possible while regularly monitoring their high-risk or affected limb.[8] In addition to the importance of physical exercise in general health, weight control, and QOL, physical exercise can promote lymph fluid drainage through large muscle movement. Individuals should be instructed to perform physical exercise according to the general exercise guidelines[8]: (1) initiate exercise at lower intensity gradually increasing intensity as tolerated, monitoring the at-risk limb/s for signs and symptoms of swelling; (2) exercise to the extent that the affected body part is not fatigued; (3) modify physical exercise to reduce the risk of trauma and injury; and (4) use a compression garment during exercise if recommended by healthcare professionals with lymphedema training.

Case Study: A Patient with Ovarian Cancer

Ms. S is a 51-year-old woman who underwent a total abdominal hysterectomy and bilateral salpingo-oophorectomy in April 2008 (TAH BSO 4-08) for ovarian cancer. She received postop external beam radiation treatment to her abdomen and pelvis. Postoperatively, she developed a pelvic abscess, sigmoid perforation, and an ileovaginal fistula. The fistula and perforation were repaired, and an ileostomy was done. Ms. S stated that the swelling in her right lower extremity began after the fistula repair and ileostomy surgery 12/12. She presented for evaluation in February 2013 with genital swelling and fluid leakage from vagina as well

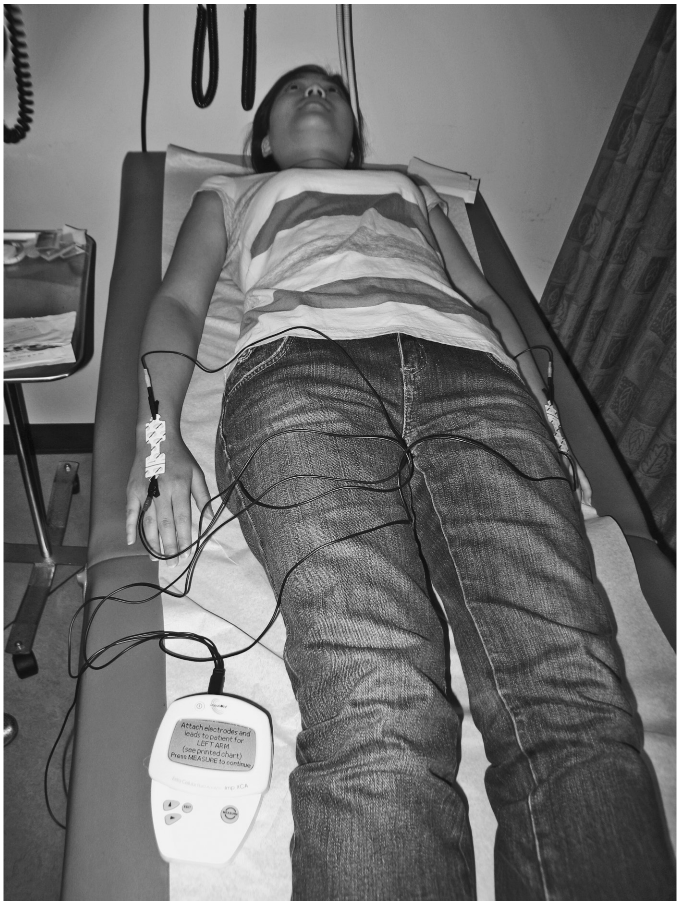
Attach electrodes and leads to patient for LEFT ARM (see printed chart) Press MEASURE to continue

Figure 18.3 Bioelectrical impedance analysis (ImpXCA).
Source: Mei R. Fu. All rights reserved.

as moderate pitting edema of her right lower extremity, toes to groin, with complaint of ache and heaviness 4 out of 10 (4/10). She denied swelling in her left lower extremity, which was at risk because of lymph node dissection (LND) and radiation treatment (XRT). The skin of both lower extremities was intact but taut with a slight violaceous discoloration suggestive of some venous impairment. She had chemotherapy-induced peripheral neuropathy in both feet (CIPN both feet), chronic low back pain (chronic LBP) related to herniated disc L5–S1, hypertension, adult onset diabetes mellitus, hypothyroidism, and asthma. Patient scored herself 52% impairment on the Lower Limb Functional Index tool. She reported that her right lower extremity and pelvic area become more swollen and painful as the day progresses, limiting her ability to walk or drive any distance. Ms. S was taking ibuprofen and oxycodone/acetaminophen to control her pain and duloxetine for depression. Pretreatment volume difference between legs was 49.7% (5,288 mL). Complete decongestive therapy (CDT) 5 days per week for 4 weeks was recommended to address Ms. S's goals to decrease her pain, tightness, and edema in her right lower extremity and genital area as feasible, improve collateral lymph drainage from her lower extremities and trunk to the axillae, and increase her endurance for functional activities as tolerated. Ms. S needed to be able to walk long distances and wanted to drive with her eldest son, a high school senior, to visit colleges. At the completion of treatment, she did achieve an 81% (4,270 mL) reduction in volume in her right lower extremity and a reduction in the genital swelling. She was fitted with custom flat-knit chap and thigh-style compression stockings Class 3 (36.1–44.5 mm Hg compression) for the right lower extremity. Pantyhose, while theoretically optimal to apply pelvic and abdominal compression, were not feasible because of abdominal discomfort, and her ileostomy appliance often leaked, causing her great distress. She was fitted with a custom thigh-length inelastic foam and fabric compression legging for night compression on her right lower extremity. She did obtain an inexpensive, ready-to-wear, lightweight microfiber panty shaper (we cut out a window for the ileostomy appliance) to provide some genital compression when she could tolerate it. Initially, post CDT treatment, she was able to walk longer distances with more comfort; she made several college visits with her eldest son and was able to take a family vacation with her husband and two sons. However, her back and abdominal pain increased and she was later admitted to the hospital with a bowel obstruction from progression of the cancer. She was able to control her swelling in the hospital with her inelastic compression legging, which she donned with nursing assistance. Although her disease progressed, she was able to obtain some relief of the pain and heaviness as well as reduce her risk for cellulitis infection in her right leg. She was happy that by treating her lymphedema, she was able to travel with her son to help him choose the college he wanted to attend the next year.

Case Study: A Patient with Lymphedema

Mrs. M is an 84-year-old woman with a history of swelling in right upper extremity (RUE). Mrs. M was diagnosed with right breast cancer after sudden onset of swelling in right arm. Mrs. M had a right mastectomy with axillary dissection and hormone therapy followed by four cycles of chemotherapy. Mrs. M self-scored the heaviness and discomfort in her RUE as 5/10. She denied pain and scored 8% impairment on the Quick Dash Upper Extremity Functional Tool.

Mrs. M was left-hand dominant, but was able to perform multiple activities with both arms. There was severe mixed pitting and fibrotic, nonpitting edema of the RUE from the fingers to axilla, extending into right posterior axilla and right lateral trunk. Skin of the right chest wall was adherent and puckered. The skin of the RUE had a pinkish, violaceous discoloration typical of malignant lymphedema. Multiple small varices were visible on the right shoulder that extended to the anterior axillary line, suggestive of malignant lymphedema. Circumferential measurements taken of both upper extremities revealed differences as follows: mid hand 1.7 cm, wrist 3.8 cm, forearm 8.8 cm, elbow 8.5 cm, upper arm 14.7 cm, and axilla 9.8 cm. Mrs. M had impaired range of motion (ROM) in the RUE as follows: shoulder flexion was 0–120 degrees, shoulder abduction was 0–90 degrees, internal and external rotation were 0–60 degrees, elbow flexion was 0–110 degrees, wrist flexion was 0–10 degrees, and wrist extension was 0–45 degrees.

Mrs. M started a 4-week course of lymphedema treatment after she completed external beam radiation treatment to the right chest and axilla. She stated that she did not have any significant burns during the radiation treatment. Lymph drainage followed the right axillo-inguinal collateral lymph pathway, and multilayer, short-stretch compression bandages were applied to the RUE from the fingers to the axilla. Foam chip pads were placed under the compression bandages and they greatly reduced the fibrotic tissue in the RUE. The wound in the right axilla healed slowly. A custom elastic compression arm-sleeve and glove (Compression Class 1–20 mm Hg) were ordered for daytime compression, and a ready-to-wear foam and fabric alternative compression sleeve and gauntlet were provided for night compression. Mrs. M was instructed in a modified exercise program emphasizing abdominal breathing exercises. At the end of her 4-week course of treatment Mrs. M's RUE exhibited a reduction of 34.7 cm or 47%, comparing it with her uninvolved LUE. She self-scored the heaviness and discomfort in her RUE as 3/10, an improvement from 5/10 prior to treatment.

At Mrs. M's 1-month follow-up, her RUE was stable, so she was scheduled for a 3-month follow-up. Her RUE began to show increase in edema causing her difficulty in wearing her compression garments and compression bandaging. Mrs. M was placed on oxygen due to shortness of breath. Pulmonary lesions were suspected and test results were pending. Mrs. M lost some of her initial edema reduction, which now measured 28.9 cm/37% at this 3-month follow-up. At her 8-month follow-up Mrs. M's RUE exhibited a significant increase in swelling: 55 cm from initial baseline measurements. An unusual rash was noted on Mrs. M's chest and back at this time. Her daughter was encouraged to have Mrs. M seen by her oncologist. The diagnosis of recurrent cancer was made. Mrs. M started a course of palliative lymphedema treatment. Multiple open, draining skin lesions were present on the right chest wall, in the right axilla, and on the proximal portion of the right upper arm. Mrs. M was in severe pain but refused to take pain meds. She had a difficult time lying on the treatment table due to pain. Modified positioning with Mrs. M sitting facing the treatment table with her arms supported on a pillow was used. We encouraged Mrs. M to take her pain meds at home prior to coming to treatment. Mrs. M experienced severe itching during treatment. She was resistant to taking her opioid pain medications. She began to develop swelling in her lower extremities. Upon questioning, Mrs. M's daughter revealed that her mom was not taking her prescribed diuretic (diuretics are not a treatment for lymphedema itself, but are helpful in cases of malignant lymphedema or when there are medical comorbidities that require diuretic treatment). We encouraged her to take her medication as prescribed and contacted her oncologist to advise them of this. The custom elastic arm-sleeve and glove she had from her initial course of treatment in October 2013 would no longer fit because of the marked increase in her edema. She was measured for a custom inelastic Velcro adjustable arm-sleeve and gauntlet.

Mrs. M's chest lesions began to drain profusely, and her pain worsened significantly as her malignant disease progressed. Her family members were instructed in donning the Velcro compression garments and compression bandaging for home use as tolerated. She was discharged from palliative treatment. Mrs. M was admitted to hospice care and expired. Her family was grateful that they were able to assist in Mrs. M's care in those last months and felt that having some tools to help control the swelling gave both Mrs. M and the family some measure of comfort during a difficult time.

Edema Treatment

Edema treatment focuses on detection and intervention related to the causative factor or factors. Effective treatment stabilizes the interstitial fluid volume.[23] Tissue support and/or gentle compression can be useful in relieving edema that might progress to lymphedema.

Lymphedema Treatment

Lymphedema treatment refers to therapies to help reduce swelling and associated symptoms as well as maintain reductions achieved through treatment while minimizing exacerbations of swelling. Treatments include surgery, pharmacological therapy, and CDT.[8,9] Pharmacological therapy and surgery have limited proven effectiveness. Although diuretics are not recommended for the treatment of lymphedema and are proved to be ineffective,[8] there are cases where lymphedema is combined with edema from other comorbid conditions such as heart or renal failure in which diuretics are part of the medical management of these combined edemas. Patients may have heard that "diuretics are not a treatment for lymphedema," and they need to be cautioned to continue their diuretics if they have been prescribed to treat hypertension, heart or renal failure, or other comorbid conditions.

Surgical Approach

A recent systematic review for research from 2009 to 2014 concludes that the effectiveness of surgical treatment for lymphedema has not been established.[8] The various surgical treatment options for lymphedema can be broadly categorized as excisional procedures, liposuction, lymphatic reconstruction, and tissue transfer procedures. In the past decade, significant progress has been made in contemporary surgical treatment for lymphedema, particularly microsurgical procedures (e.g., lymphaticovenous anastomosis, vascularized lymph node transfer, and lymphaticolymphatic bypass). With proper diagnosis and the careful selection of the appropriate procedure, surgical techniques can be used to treat lymphedema in patients when combined with integrated lymphedema therapy.[8,31] However, the efficacy and long-term outcomes of the surgical approaches in this population have yet to be reported. At this point, surgical treatment of lymphedema is reserved primarily for patients who have lymphedema that is refractory to standard treatment modalities.[8,31]

Complete Decongestive Therapy

CDT or decongestive lymphatic therapy (DLT) evolved in Europe when Michael Foldi[8,9,26,31] combined Vodder's manual lymph drainage (MLD) technique with bandaging, exercises, and specialized skin care. Dr. Foldi described his four-modality lymphedema treatment as "complete decongestive therapy." CDT is the current standard of care for treatment of lymphedema. It consists of an intensive lymphedema therapy (phase I of CDT) followed by an ongoing, individualized maintenance and self-management phase (phase II of CDT).[8,9,26,31] In the intensive therapy phase, therapists use MLD, compression garments, multilayer short-stretch compression bandaging, remedial exercise, and skin care to reduce visible or palpable swelling.[8,9,26,31] The duration of the intensive lymphedema therapy phase, averaging about two to three treatments per week for up to 8 weeks, varies with the severity of lymphedema and patient response. Clinically, phase I of CDT ends when swelling has been reduced and symptoms have been controlled. Following the completion of intensive lymphedema therapy, the patient is taught to initiate self-management (phase II of CDT) for control of chronic soft tissue changes and to conduct the individual components of CDT, including self-MLD, skin care, exercises, and application of prescribed compression garments and/or bandages to prevent exacerbation of swelling and symptoms. The self-management phase is a lifelong process; regular check-ups with the primary care provider and the lymphedema therapist are necessary.[8,9,26,31]

Adherence to the prescribed treatment can be difficult because even the most customized garments or sleeves sometimes are uncomfortable, unsightly, and laborious to put on.[16,21] A constellation of complex factors (e.g., physical, financial, aesthetic, time) can influence survivors' adherence with treatment. Lymphedema is a complex condition that needs to be treated by therapists with special training and experience in this field, as outlined by the National Lymphedema Network position paper on educational training for lymphedema therapists (http://www.lymphnet.org/pdfDocs/nlntraining.pdf) and the Lymphology Association of North America (LANA) (http://www.clt-lana.org/). These multidisciplinary organizations have outlined training requirements for clinicians to gain certification in this field.

Bandages and Garments

Both compression garments and bandages are effective in treating lymphedema by providing proper compression to improve muscle and joint pumps during activity, to aid in moving lymph fluid from the affected area, to prevent the reaccumulation of evacuated lymph fluid, and to maintain the results achieved during MLD.[8,9,26,31]

Compression bandages or multilayer lymphedema bandaging (MLLB) are an effective and flexible form of compression, particularly in the early stages of lymphedema therapy. MLLB provides external compression. For some patients, MLLB may be used as part of long-term or palliative management. MLLB uses inelastic or low-stretch bandages to produce a massaging effect and stimulate lymph flow and is especially important for patients with severe lymphedema, such as lymphedema complicated by morbid obesity or neglected primary lymphedema. It is also important for patients who choose self- or caregiver-bandaging to enhance comfort or for nighttime compression when they wear a compression garment during the day.[8,9,26,31] Foam or other padding is often used under bandages to improve edema reduction, soften fibrosis, and restore normal limb contours. The time, effort, and dexterity required for bandaging can become burdensome and is not practical or possible for some patients, necessitating the use of an alternative compression method.[27] MLLB should be avoided for the following conditions: (1) severe arterial insufficiency with an ankle/brachial index (ABI) of less than 0.6, although modified MLLB with reduced pressures can be used under close supervision; (2) uncontrolled heart failure; and (3) severe peripheral neuropathy.[37] Some components of the MLLB system can be washed and dried according to the manufacturer's instructions and reused. Over time, inelastic bandages will progressively lose their extensibility, which will increase their stiffness. Heavily soiled, cohesive, and adhesive bandages should be discarded after use.[8,9,26] Patients with lymphedema graduate from bandages to elastic compression garments. Compression garments generally need to be worn throughout the patient's life.

Compression garments are recommended for patients with lymphedema of the extremities.[8] Compression garments may be used in the initial management of patients who have mild upper or lower limb lymphedema with minor pitting, no significant tissue changes, no or minimal shape distortion, or palliative needs.[8,9,26,31] Proper fit of the compression garment is imperative. An ill-fitting garment can cause swelling to develop in an area proximal or distal to the end of the garment (i.e., in the hand or in the anterior or posterior axillary/shoulder areas or in the toes or genital/pubic/buttock/abdominal areas). Patients must be instructed to remove their garment if this type of swelling, pain, numbness, or muscle cramps occur and consult with their lymphedema specialist regarding revision of the garment to ensure proper fit and function. Gradient compression provides the greatest pressure distally and less pressure proximally; this is optimal for improved lymphatic transport.[38,39] Skin care, exercise or body movement, elevation, and self-lymph drainage should be taught, along with self-monitoring to help to relieve lymphedema symptoms in individuals receiving palliative care. Patients should be reassessed 4–6 weeks after initial fitting and then approximately every 3–6 months.[38,39]

Compression garments should be laundered every time they are worn and replaced every 3–6 months. Patients need to moisturize and check their skin daily for signs of irritation/infection. A variety of helpful products exist to assist patients in applying garments, which may be an especially challenging task for elderly and disabled patients. Usually, ridged rubber gloves (dishwashing gloves) facilitate application of garments and extend their longevity. Timely garment replacement (usually every 6 months) is essential for good edema control.[38,39] If a compression garment causes pain, neurological symptoms, or color or temperature changes, it should be removed and the patient instructed to consult with his or her lymphedema specialist to resolve the problem.

Pneumatic (Mechanical) Pumps: Intermittent Pneumatic Compression Devices

Mechanical pneumatic pumps use electricity to inflate a single-chamber or multichamber sleeve that produces external limb compression. A decreased tissue capillary filtration rate facilitates tissue fluid reduction and, consequently, limb volume decrease.[8,40] A recent systematic review on research from 2009 to 2014 concluded that the effectiveness of pneumatic compression devices (PCDs) on limb volume reduction has not been established; furthermore, adverse events related to PCD use are reported, such as increased swelling of hand and torso, forearm pain, finger numbness, and pain in the axilla and back.[8] After more than 50 years of pump use in lymphedema care and long-established Medicare reimbursement, no guidelines exist, significant complications are reported, and research has not clarified benefit. Clearly, more studies with rigorous design and adequate sample sizes are needed.[8]

Infection Prevention and Treatment

Infection is the most common lymphedema complication.[10] Lymph stasis, decreased local immune response, tissue congestion, and accumulated proteins and other debris foster infection.[2] Traditional signs and symptoms (fever, malaise, lethargy, and nausea) are often present. Decades of literature support prompt oral or intravenous antibiotic therapy.[31] Because streptococci and staphylococci are frequent precipitators, antibiotics must have good skin penetration and cover normal skin flora, as well as gram-positive cocci.[9,31] Early detection and treatment of infections can help prevent the need for intravenous therapy and hospitalization.[9,31] Intravenous antibiotic therapy is recommended for systemic signs of infection or insufficient response to oral antibiotics. Nursing activities include assisting patients in obtaining prompt antibiotic therapy, monitoring and reporting signs and symptoms, and providing instruction regarding high fluid intake, rest, elevation of the infected limb, and avoidance of strenuous activity. Garment-type compression is encouraged as soon as tolerable during infection. Wound care or infectious disease specialists can be helpful in complicated cases. Infection prophylaxis has been highly effective for patients who experience repeated serious infections or inflammatory episodes.[31] Effective edema reduction and control may also help reduce the incidence of lymphedema infection.[31,41]

The feet, which are especially susceptible to fungal infections in lower extremity lymphedema, can exhibit peeling, scaly skin, and toenail changes. Antifungal powders are recommended prophylactically. Antifungal creams should be used at the first sign of fungus. Diabetic-like skin care and use of cotton socks and well-fitted, breathable (leather or canvas), sturdy shoes are beneficial.[31,41]

Lymphedema Management

Edema usually subsides with proper treatment, whereas lymphedema is a lifelong and chronic condition requiring long-term management.[8,9,16,31] Lymphedema management focuses on daily activities and strategies undertaken to decrease the swelling, relieve symptom distress, and prevent acute exacerbations and infections.[8,9,16,31] Components of long-term lymphedema management are listed in Box 18.2 and described throughout the chapter. Long-term management is a process of fostering optimal physical, functional, psychosocial, and spiritual wellness. Spiritual care guidelines have been gradually evolving in nursing for several decades. Spiritual care supports patients' efforts to make meaning out of illness and to redefine themselves in their new state of being. Specific spiritual interventions can include (1) support during the struggle with and exploration of life's ambiguities, (2) acknowledgment of patients' real and potential losses and victories, and (3) guidance in patients' exploration of end-of-life issues and decisions.[8,9,16,31]

Lymphedema management necessitates a multidisciplinary approach.[9,31,42] Nurses should assess for signs of infection, changes in limb volume or limb size, as well as limb or torso contour, pain, and degree of swelling at each patient visit. Additional inquiries need to be made as to any other symptoms patients may be experiencing because of the lymphedema. Nurses should assess self-care behaviors and encourage patients with lymphedema to wear their compression garment as prescribed. Patients with new-onset or worsening lymphedema should be referred to certified lymphedema therapists for volume reduction treatment. Antibiotics may be prescribed for infections. Certified lymphedema therapists provide assessment and treatment for the swollen limb or area as well as any musculoskeletal impairment that may develop as a consequence of surgery, radiation, and or chemotherapy to treat cancer. In addition, certified lymphedema therapists also design individualized patient education about self-care practices, skin care, wear and care of compression garments, exercise and exercise progression based on individual lymphedema risk factors, and level of fitness. Certified lymphedema therapists have the expertise to recommend home and workplace modifications if needed to reduce risk for injury or overuse of the at-risk or affected limbs. Collecting and reviewing outcomes with patients over time fosters ongoing instruction, complication prevention, sustained lymphedema improvement, and patient empowerment.[9,31,42]

Box 18.2 Components of Long-Term Lymphedema Management

- History, physical examination, and ongoing assessment and support
- Individualized and holistic care coordination
- Multidisciplinary referrals
- Comprehensive initial and ongoing patient instruction
- Ongoing psychosocial support
- Promotion of ongoing optimal self-care management
- Facilitation of appropriate evidence-based, individualized treatment
- Patient and practice outcome measurement
- Access and long-term follow-up and management
- Communication and collaboration with related healthcare providers

Pain and Lymphedema Symptom Management

Approximately 30–60% of patients with lymphedema post breast cancer treatment reported pain.[3,10,15,20, 37] Causes of pain included infection, postoperative changes in the axilla, postmastectomy pain syndrome, brachial plexopathy, various arthritic conditions, peripheral entrapment neuropathies, vascular compromise, and cancer recurrence. Sudden onset of pain requires careful assessment for complications. Use of the 0–10 pain scale is recommended for cancer pain assessment.[3,10,15,20, 37] Standard pain management principles are applicable for lymphedema-related pain.

Self-Care

Optimal patient self-care typically includes adherence to risk-reduction behaviors, use of compression, weight management, fitness and lymphedema exercises, optimal nutrition and hydration, healthy lifestyle practices, and seeking assistance for lymphedema-related problems.[8,30] Patient empowerment for optimal self-care is a great impetus to long-term management success.[8,9] Evidence from breast cancer patients indicates that weight management, including reduction of body mass index or weight, appears to be an effective means of assisting in the reduction of arm volume during lymphedema treatment.[8]

Exercise

Exercise or body movement is an integral part of lymphedema management and risk reduction. Exercise improves muscular strength, cardiovascular function, psychological well-being, and functional capacity.[8] Research evidence from patients with upper extremity lymphedema have clearly shown that exercise (e.g., progressive weight lifting and other resistance exercises) under close supervision is not associated with a worsening of lymphedema or related symptoms. Exercise may help stabilize limb volume and improve joint mobility in the affected area.[8]

Gentle resistance exercise stimulates muscle pumps and increases lymph flow; aerobic exercise facilitates changes in intraabdominal pressure, which facilitates pumping of the thoracic duct.[8] A tailored exercise or body movement program that combines flexibility, resistance, and aerobic exercise may be beneficial in reducing the risk of and controlling lymphedema. General exercise guidelines include the following[8]:

- Start with low to moderate intensity exercise.
- Walking, swimming, cycling, and low impact aerobics are recommended.
- Flexibility exercises should be performed to maintain range of movement.
- Appropriate warming up and cooling down phases should be implemented as part of exercise to avoid exacerbation of swelling.
- Compression garments should be worn by individuals with lymphedema during exercise.

Skin Care

Skin care is important for lymphedema risk reduction and management, which optimizes the condition of the skin and prevents infection.[8,9,31] Lymphedema can cause skin dryness and irritation, which is increased with long-term use of compression products. Bland, unscented products are recommended for daily cleansing and moisturizing.[8,9,31] Low pH moisturizers, which discourage infection, are recommended for lymphedema because skin and tissue changes increase infection risk. Water-based moisturizers, which are absorbed more readily, are less likely to damage compression products but are not suitable for all patients. Cotton clothing allows ventilation and is absorbent.

Advanced lymphedema can cause several skin complications, including lymphorrhea, lymphoceles, papillomas, and hyperkeratosis. *Lymphorrhea* is leakage of lymph fluid through the skin that occurs when skin cannot accommodate accumulated fluid. Nonadherent dressings, good skin care, and compression are used to alleviate leakage. Compression and good skin care also reduce the occurrence of lymphoceles, papillomas, and hyperkeratosis; these complications reflect skin adaptation to excess subcutaneous lymph.

Unusual Lymphedemas

Palliative care may require the management of unusual and challenging lymphedema sites, such as breast, head, neck, trunk, or genitals.[39,42] MLD, skin-softening techniques, foam chip pads, and external compression (if possible) are recommended.[42] External compression may be achieved with collars, vests, custom pants or tights, scrotal supports,[42] or spandex-type exercise apparel. The assistance of occupational or physical therapists and a seamstress may be helpful. Nationally, instructional courses are available to provide guidance for managing these difficult lymphedemas. Therapists can obtain professional certification for lymphedema treatment from the Lymphology Association of North America (LANA) (http://www.clt-lana.org/). Box 18.3 presents detailed information about neck lymphedema from head and neck cancer.

Box 18.3 Lymphedema Secondary to Cancer of the Head and Neck

Lymphedema secondary to head and neck cancer commonly presents following surgery and radiotherapy. Lymphedema is frequently found below the chin in the anterior neck. Difficulty in swallowing and breathing are the major symptoms causing distress from neck lymphedema. Mild swelling often progresses fairly rapidly to firm, nonpitting swelling and thus may often not be recognized or treated as lymphedema.

Quantification of neck edema can be achieved by measuring from the tip of one ear lobe to the tip of the contralateral ear lobe along the line of the chin, and then measuring this distance for every 2 cm (or 4 cm) interval down to the intersection of the neck and chest. Quantifiable outcome measurement over time fosters patient participation, improved long-term outcomes, and might be beneficial as substantiation for third-party payers.

Compression supports used after cosmetic facial surgery can be useful for neck lymphedema. These products provide gentle compression to the chin using two sets of long narrow Velcro straps that extend from the chin to the top of the head and to the back of the neck. This size-adjustable "chin strap" provides gentle, size-adjustable compression to the chin and neck. Patients are encouraged to use the product continually for at least several weeks or a month to achieve optimal edema reduction. Although lifelong product use is encouraged for optimal lymph function, some patients have been able to transition to mainly night-time product use and still maintain acceptable edema control.

Nursing interventions for head and neck lymphedema include:

- Help patients to make an informed decision in a supportive environment.
- Instruction and support in establishment of a lifelong daily self-care regimen including range-of-motion exercises, skin assessment, and application of moisturizers and early, skilled patient complication assistance and use of safe external compression. A written self-care program may foster patient self-care adherence.
- Monitor external neck compression. External neck compression must provide sufficient pressure to stimulate lymphatic function without causing skin irritation/injury or impairment of breathing, eating, or swallowing.
- Encourage the use of daily self-care using MLD and exercises for facial, neck, and postural muscles to further improve edema control and posture.
- Document patient outcomes, including interval neck circumferences, skin integrity, pain level, and neck range of motion.

Conclusion

Edema is a symptom usually relieved by addressing the causative factor. Lymphedema is a chronic disorder that requires lifelong management. Oncology nurses and other nurses have increasingly contributed to lymphedema management as they have improved cancer survivorship. Nursing's unique focus and scope of practice is ideally suited to chronic illness management, both at entry and advanced practice levels. To meet the physical and psychological needs of patients, nurses and other healthcare professionals must make an effort to understand the pathophysiology and chronic nature of lymphedema, as well as its physical, functional, and psychosocial impact. Armed with such information, nurses can then engage patients in supportive dialogue about risk reduction and lymphedema management.[8,9] With the advent of precision health that aims at discovering the right treatment, for the right patient, at the right time, as well as determination of factors contributing to or protecting from common and complex diseases, researchers started to explore the role of inherited genetic susceptibility and the pathogenesis of lymphedema.[43]

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CHAPTER 19

Palliative Wound, Ostomy, and Continence Care

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Key Points

- Palliative wound, ostomy, and continence (WOC) care emphasizes an interprofessional, patient-centered approach to alleviate suffering and promote well-being and quality of life (QOL) through the palliation of symptoms and the preservation or restoration of functional performance.
- Specialist-level WOC care guides advanced symptom and disease management with the goal of restoring normalcy and improving self-confidence, body image, socialization, and QOL.
- Palliative wound care is a dynamic, interprofessional, patient- and family-centered process that combines the principles of evidence-based wound care with the science of advanced symptom management to preserve or restore functional performance and psychological well-being, thereby promoting QOL.
- Palliative care of the patient with a urinary or fecal diversion or fistula centers on expert guidance to manage advanced symptoms and adapt product selection and utilization to the progressive cognitive, psychomotor, and physiologic decline experienced in advanced or terminal illness, with an eventual shift of responsibilities to the caregiver.
- Urinary and fecal incontinence management in palliative care balances advanced symptom control with minimally invasive, highly individualized interventions adapted to the terminally ill patient's progressive cognitive, psychomotor, and physiologic decline.

Introduction

The exact prevalence of wound, ostomy, and continence (WOC) issues in hospice and palliative care is unknown. An early study, the 1999 National Home and Hospice Survey (conducted in 1996), found that 60% of current and 80% of discharged hospice patients had incontinence, a urinary catheter, an ileostomy, or a colostomy.[1] In 2015, 1,007,753 Medicare beneficiaries died while enrolled in hospice, translating to potentially 800,000 patients with incontinence or stomas.[2] In a study of 593 patients with advanced illness, 53% of cancer patients and 67% of noncancer patients developed wounds.[3] Forty-three types of wounds were identified, with pressure injuries (PIs) accounting for 66% of all wounds.[3] PIs occurred predominately in noncancer patients, commonly on the sacrum/coccyx.[3] These numbers are staggering and certain to increase exponentially as the population aged 65 and over is projected to be 83.7 million in 2050, almost double the estimated population of 43.1 million in 2012.[4]

The rapidly escalating need for palliative WOC care in those with advanced or terminal illness is clear; however, this emerging area of palliative nursing remains poorly defined and underresearched. There is no globally accepted definition of palliative WOC nursing, but there is agreement in the literature concerning the goals of this approach, which may occur in a curative, care-a-tive, or end-of-life setting. "End of life" is defined as a terminal prognosis of 6 months or less by the Centers for Medicare and Medicaid (CMS) and National Quality Forum (NQF), who also provides a distinction between "curative" and "care-a-tive" palliative care.[5,6] Care-a-tive palliative care is provided to those with incurable conditions who are not terminally ill.[6] It is generally accepted that the overarching goals of palliative WOC nursing are to alleviate suffering and promote quality of life (QOL).[7–10]

There is consensus that palliative WOC care includes (1) expert guidance[7,10]; (2) an interprofessional team approach[7,10]; (3) a center of care that includes both the patient and their caregivers[7–10]; (4) a focus on the prevention of complications, advanced symptom management, and preservation of functional performance and well-being[10]; and (5) highly individualized care centered on respect for the patient's advance directives and preferences.[8–10]

This chapter will address palliative WOC-specific assessment, prevention, and management strategies as well as broader, general approaches to advanced symptom management, psychosocial support, maximization of functional performance, and product selection. The first part of the chapter concentrates on palliative wound care, including the concepts of skin changes at end of life (SCALE), skin failure, and avoidable versus unavoidable pressure injuries (PIs), Kennedy terminal ulcers (KTUs), and Trombley-Brennan terminal tissue injury (TB-TTI); strategies for the prevention, management, and symptom palliation of PIs; medical device–related pressure injuries, skin tears, and medical adhesive–related skin injuries (MARSIs); chronic critical limb ischemia with gangrene; malignant fungating wounds (MFWs); and less commonly encountered wounds (Marjolin's ulcers, calcinosis cutis, calciphylaxis, radiation dermatitis). The next part of the chapter will discuss the palliative management of continent and incontinent diversions and fistulas, and the last section will discuss the management of incontinence-associated dermatitis (IAD) in palliative settings.

Case Study: A Patient with Metastatic Cancer and a Colostomy

A single, 66-year-old woman with metastatic colorectal cancer, a colostomy, and multiple comorbidities presented to the inpatient hospice unit with her sister. Her sister flew in from out of state to care for the patient at end of life and found her colostomy nonfunctioning with a poorly fitting pouching system and her sister with painful, inflamed buttocks from lying in urine. The patient was now bedbound, requiring total care, with limited home health aide hours and financial resources. The patient's wish was to die at home, but her sister had no experience in caregiving and feared she didn't have the strength to perform skin care nor the knowledge to care for her colostomy. The Hospice Nurse Practitioner, also a WOC nurse, was consulted to devise a plan of care that would enable the pair to return to the patient's apartment with home hospice.

The Role of the Wound, Ostomy, and Continence Specialist

The WOC nurse plays an integral role in providing expert guidance related to WOC issues in hospice and palliative care.[11] The evolving role of the WOC specialist in these settings ideally incorporates the scope and standards of both WOC specialty practice nursing and palliative nursing.[12,13] Palliative and hospice WOC nurses are experts uniquely qualified to provide both basic and advanced care, at either the baccalaureate or advanced practice level.[11] Box 19.1 outlines the responsibilities of the WOC nurse on a hospice team or palliative care service.[10,11–13] Every hospice program should employ or consult with a WOC nurse ideally certified in hospice and palliative care (CHPN, ACHPN). Dual certification ensures a level of expertise in caring for those with advanced illness requiring palliative WOC services and allows nursing professionals to practice under the full scope of their licensure in the palliative care setting.

Case Study: Resolution

The Advanced Practice Hospice WOC nurse diagnosed acute opioid-induced constipation after a comprehensive history and a physical exam that included digitalizing the stoma. The impaction resolved after colostomy irrigation and titration of the patient's bowel regime. Upon further examination of the patient's abdomen and stoma, the APRN discovered uneven abdominal planes from new tumor burden, inhibiting adherence of the two-piece extended-wear appliance. The patient was placed in a flexible one-piece pouching system after filling in larger deficits with adhesive paste. Her sister was instructed in changing the appliance every 3 days and as needed. IAD was diagnosed after inspection of the patient's buttocks, and the patient agreed to a Foley catheter insertion. The catheter placement, in combination with a zinc-oxide barrier ointment, assisted in healing the IAD and facilitated her return home, as now her sister was able to manage her sister's urinary incontinence. The hospice home-care team seamlessly resumed care after consultation with the Advanced Practice WOC nurse.

Box 19.1 Role of the Hospice and Palliative Care Wound, Ostomy, and Continence Nurse

Educator

- Patient and caregiver education
- Staff education (orientation, staff development, faculty development)
- Profession education at the local, national, and international level

Clinician

- Specialist-level wound, ostomy, and continence intra-agency consultation
- Specialist-level consultation to outside or referring agencies
- Chair of the hospice and palliative care wound, ostomy, and continence nurse committee
- Supportive role: helping staff decision-making concerning palliative approaches to care

Researcher

- Conducts or participates in research based on the National Institute for Nursing Research: Palliative Care Research Foci:
  a. End-of-life and Palliative Care
  b. Advancing the Quality of Life: Symptom Management and Self-Management
- Promotes evidence-based nursing

Administrator

- Wound, ostomy, and continence supply management:
  a. Cost analysis and containment
  b. Formulary development
  c. Product evaluation
- Continuous quality improvement:
  a. Patient satisfaction
  b. Pressure injury prevalence and incidence
  c. Wound prevalence registry
- Policy, procedure, and protocol development

Source: Reprinted with permission from Reference 10: Tilley C, Lipson, J, Ramos, M. Palliative wound care for malignant wounds at end-of-life. *Nurs Clin North Am*. 2016;48:479–501.

Palliative Wound Care

Case Study: Wound Care

A married, 45-year-old woman on home hospice was seen by the nurse case manager for the first time. As the nurse entered the front door, he was assaulted by a foul odor that permeated the house. Upon meeting his patient, he discovered she had terminal vulvar cancer and the odor was emanating from a malignant fungating vaginal wound. She was wearing underwear with obstetric pads secondary to exudate leakage. Her husband reported she had not left the house since returning from the hospital 4 weeks ago. He explained she was profoundly embarrassed by the odor and exudate and that she had to shower and change her clothes several times a day and was "very depressed."

Palliative wound care is a holistic, integrated approach that emphasizes symptom management, enhancement of psychosocial well-being, integration of patient and family goals, and an interprofessional approach[7]. The concept of palliative wound care is still evolving, with the term first appearing in the literature in the 1980s. Since then, the palliative care and hospice movement has gained international attention, and each subsequent decade has seen a steady increase in both palliative wound care research and evidence-based literature.[7,8] There is no consensus and few explicit definitions of palliative wound care.[7] Palliative wound care is a dynamic patient- and family-centered process that utilizes an interprofessional framework to combine the principles of evidence-based wound care with advanced symptom management to preserve or restore functional performance and ultimately improve psychological well-being and QOL. Symptoms are considered advanced when conventional therapies and symptom management no longer work, exerting a negative impact on physical and psychosocial functioning and QOL.[14] Although management of advanced symptoms is a priority, it is erroneous to make the assumption that the goals of palliative wound care can never include wound healing.[15] The PALCARE mnemonic (Prognosis, Advance care planning, Living situation, Comprehensive history, Assessment, evidence-based Recommendations, and Education of patient, family and staff) is a comprehensive framework for developing a holistic, interprofessional, patient-centered palliative plan of care for patients with advanced or terminal illness and complex, nonhealing wounds (see Box 19.2).[10]

Box 19.2 A Systematic Approach to Palliative Wound Care: PALCARE

Prognosis:

- Hospice diagnosis and Palliative Performance Score (PPS)
- Is the patient's life expectancy weeks or months?
- Is the patient in the last hours or days of life?

Advance care planning:

- Goals of care
  - Further hospitalizations (under what circumstances)
  - Resuscitation wishes: full code status versus natural death
  - Antibiotics: intravenous, oral, topical
  - Medically administered nutrition or hydration
  - Emergency management clarification (hemorrhage, sepsis)
- Advance directives
  - Complete MOLST, POLST, Health Care Proxy, Living Will

Living situation:

- Caregiver availability
- Caregiver participation (willingness)
- Caregiver ability (cognitive/physical)
- Caregiver reliability
- Environment/setting (domiciled vs undomiciled, running water, shower facilities)
- Fiduciary or food insecurity
- Consider appropriate hospice level of care
  - Inpatient hospice (IPU) for uncontrolled symptoms
  - Hospice home care (symptoms manageable in the community)
  - Respite care (caregiver is overwhelmed or unavailable)

Comprehensive history:

- Review of symptoms, activities of daily living, complementary alternative medicine
- Wound(s) and associated symptoms (pain, pruritus odor, exudate, bleeding, lymphedema, bulk effect of wound or dressing, number of dressing changes, current dressing plan)
- Psychiatric (Patient Health Questionnaire 2, Generalized Anxiety Disorder 7)[125]
- Social (legal status, insurance, employment, fiduciary/housing/food insecurity)
- Spiritual (FICA tool)[127]

Assessment:

- Comprehensive physical assessment
- Focused wound assessment
- Wound photographs (follow institution policy)
- Wound cultures, laboratory studies (as necessary)

Recommendations:

- Establish symptom management priorities (pain, pruritus, odor, exudate, bleeding, lymphedema, bulk effect of wound or dressings) and palliative wound care goals
- Topical and/or systemic interventions
- Referrals: wound, ostomy and continence nurse (if not already involved), psychiatry, spiritual care, social work, and so forth

Education:

- Patient, family, caregivers
- Staff education
- Hospice medical directors, administrators, wound care resource nurses

Source: Reprinted with permission from Reference 10: Tilley C, Lipson, J, Ramos, M. Palliative wound care for malignant wounds at end-of-life. *Nurs Clin North Am*. 2016;48:479–501.

Skin Changes at Life's End and Skin Failure

The concepts of SCALE, skin failure, TB-TTI, KTUs, and unavoidable PIs have received growing attention over the past decade as practitioners struggle to define and classify these underresearched phenomena, relying primarily on expert opinion and consensus.[16] SCALE is defined as physiological changes occurring as a result of the dying process that may affect the skin and soft tissues and may manifest as objective changes in skin color, turgor, or integrity, or as subjective symptoms such as localized pain.[17] In 2009, an expert panel utilized a modified Delphi process to reach consensus on 10 statements describing the etiology, risk factors, signs and symptoms, and management of SCALE (see Table 19.1).[17]

The skin is the largest organ of the body and is vulnerable to organ dysfunction and failure.[17] Skin failure is a clinical syndrome, "the state in which tissue tolerance is so compromised that cells can no longer survive in zones of physiological impairment such as hypoxia, local mechanical stresses, impaired delivery of nutrients, and buildup of toxic metabolic byproducts."[16] Skin failure occurs across the illness continuum and may be classified as acute, chronic, or end-stage.[18] Acute skin failure is an event in which critically ill patients experiencing hemodynamic instability become hypoperfused, leading to skin and underlying tissue death.[18] A study of 549 ICU patients found five variables significantly and independently associated with skin failure: peripheral arterial disease, respiratory failure, mechanical ventilation, liver failure, and severe sepsis/septic shock.[19] Chronic skin failure results in skin and underlying tissue death due to hypoperfusion in patients with a chronic disease state such as peripheral arterial disease, nephropathy, diabetes, or neurodegenerative disorders.[18] Hypoperfusion concurrent with end of life that leads to skin and underlying tissue death is termed *end-stage skin failure*.[18]

Kennedy Terminal Ulcers, Trombley-Brennan Terminal Tissue Injuries, and Avoidable vs. Unavoidable Pressure Injuries

Rapidly developing sacral ulcers in actively dying patients were first described in 1877 by French physician Jean-Martin Charcot, who termed the wound *decubitus ominosus,* as most died shortly thereafter.[20] More recently, terminal wounds over bony prominences (KTUs) and in tissues not prone to pressure (TB-TTIs) have been described parallel to the evolving attributes that define avoidable versus unavoidable PIs.[21–23]

In 1989, the term "Kennedy terminal ulcer" was coined to describe wounds that commonly develop anywhere from 24 hours to 8 weeks prior to death, are ominous prognostic signs, often progress to full-thickness wounds, and are commonly attributed to the hypoperfusion seen in end-stage skin failure.[21,24,25] These ulcers have five essential characteristics: sacrococcygeal location; a butterfly or pear shape; purple, red, blue, or black color (often variegated); sudden onset; and irregular borders.[21,24,26]

TB-TTIs are spontaneously appearing skin alterations that rapidly evolve and enlarge over areas of little to no pressure, such as the thighs, and that may display mirror imaging in patients at the end of life.[22] A study of 80 adult patients in a palliative care unit found that the median time of identification of a TB-TTI to death was 36 hours.[22] The wounds presented over seven different locations on the trunk and upper and lower extremities, both anteriorly and posteriorly, were of varying morphology, and, strikingly, 79 out of 80 wounds remained intact to time of death.[22] Renal (19%) and neurological (19%) diseases were the main diagnosis of these patients, with primary cardiac comorbidities most prevalent (42%).[22] Both KTUs and TB-TTIs are considered unavoidable skin ulcers and do not imply poor quality of end-of-life care.[27]

In 2016, the Wound, Ostomy, Continence Nurses Society (WOCN Society) published an updated position paper on avoidable versus unavoidable PIs, affirming that not all PIs are preventable. The definitions were originally developed by the Centers for Medicare and Medicaid (CMS) for long-term care standards[28,29] but were broadened and applied to all clinical practice settings by the National Pressure Ulcer Advisory Panel (NPUAP).[30] The current definitions are:

Avoidable pressure injury: An avoidable pressure injury can develop when the provider did not do one or more of the following:

Table 19.1. SCALE consensus statements

Statement 1	Physiological changes that occur as a result of the dying process may affect the skin and soft tissues and may manifest as objective changes in skin color, turgor, or integrity, or as subjective symptoms such as localized pain.
Statement 2	The plan of care and patient response should be clearly documented and reflected in the entire medical record.
Statement 3	Patient-centered concerns should be addressed including pain and activities of daily living.
Statement 4	SCALE area reflection of compromised skin (reduced soft-tissue perfusion, decreased tolerance to external insults, and impaired removal of metabolic wastes).
Statement 5	Expectations around the patient's end of life goals and concerns should be communicated among members of the interprofessional team and the patient's circle of care (potential for SCALE, skin breakdown, pressure injuries).
Statement 6	Risk factors, symptoms, and signs associated with SCALE have not been fully elucidated, but may include weakness, progressive immobility, suboptimal nutrition, diminished tissue perfusion, impaired immune function, and loss of skin integrity.
Statement 7	A total skin assessment should be performed regularly and document all areas of concern consistent with the wishes and condition of the patient.
Statement 8	Consultation with a qualified healthcare professional is recommended for any skin changes associated with increased pain, signs of infection, skin breakdown, and whenever the patient's circle of care expresses a significant concern.
Statement 9	The probable skin change etiology and goals of care should be determined. The 5 P's is recommended for determining strategies: prevention, prescription, preservation, palliation, and preference.
Statement 10	Patients and concerned individuals should be educated regarding SCALE and the plan of care.

evaluate the individual's clinical condition and PI risk factors; define and implement interventions consistent with individual needs, individual goals, and recognized standards of practice; monitor and evaluate the impact of the interventions; or revise the interventions as appropriate.

Unavoidable pressure injury: An unavoidable PI can develop even though the provider evaluated the individual's clinical condition and PI risk factors; defined and implemented interventions consistent with individual needs, goals, and recognized standards of practice; monitored and evaluated the impact of the interventions; or revised the approaches as appropriate.

A retrospective study of 20 patients who developed hospital-acquired pressure ulcers (injuries) despite appropriate risk assessment and prevention identified 10 prevalent physiologic comorbidities: hypoalbuminemia, severe anemia, respiratory failure with intubation, hypoxia with sedation or chemical paralysis, hypotension, infection or sepsis, malignancy, diabetes, renal failure, and/or congestive heart failure.[31] These comorbid conditions mirror hospice eligibility criteria and are common comorbidities encountered in those with advanced or terminal illness. Experts have additionally identified malnourishment, advanced age, dehydration, and obesity as factors contributing to unavoidable pressure injuries[32] as well as hospitalization in a critical care unit,[31,33,34] corticosteroid use,[35] and treatment with vasopressors.[33]

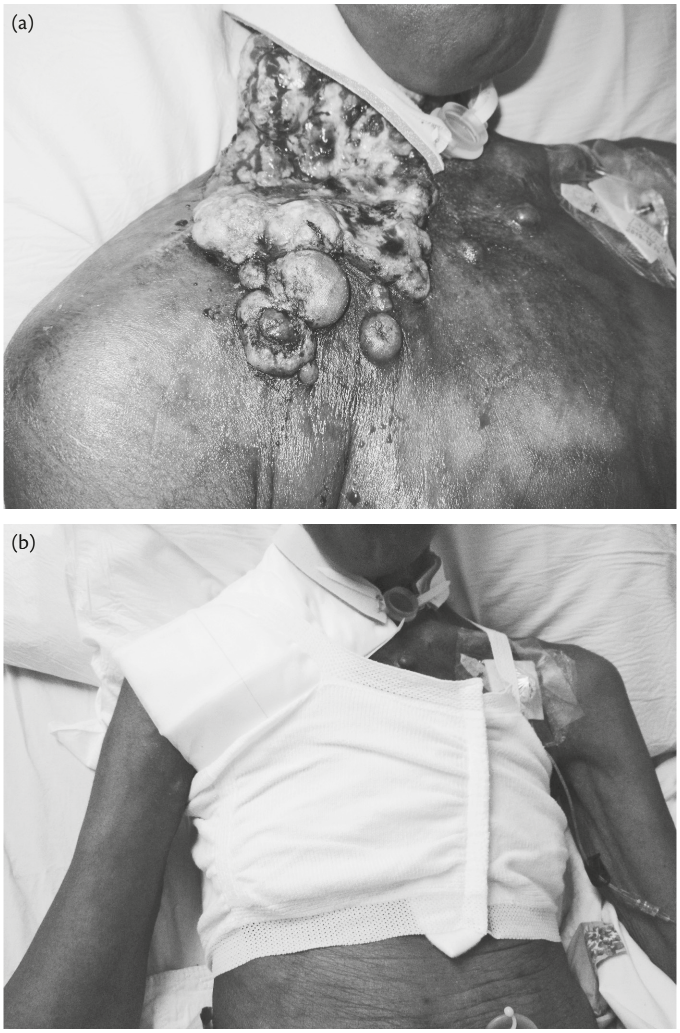


Figure 19.1 Fungating wound of head and neck extending to right chest wall before (A) and after (B) dressing change secured with surgical bra.

Advanced Symptoms in Complex and Nonhealing Wounds

A combination of traditional pharmacologic therapies, basic and advanced dressings, debridement, complimentary medicine, and cognitive behavioral therapy are used in palliative wound care to manage pain, pruritus, infection, odor, exudate, bleeding, lymphedema, and bulk effect of the wound or dressings (Figure 19.1).[10,36,37]

Pain: The skin has the most sensory nerve endings of any organ in the body and has special nociceptors that can perceive mechanical, thermal, or chemical injury, which may be somatic, neuropathic, or mixed in nature.[38] Pain occurs in up to 84% of patients with pressure ulcers, reported both at rest and with dressing changes.[39] The prevalence of MFW pain is 30.2–77.3%.[40,41] Pain descriptors in breast cancer wounds point to a mixed neuropathic and somatic etiology and an association with wound status (morphology, tissue type, size, symptoms).[40] Lower extremity wound pain has been identified in several qualitative and quantitative studies as the worst advanced symptom reported by patients with lower extremity ulcers.[42] Box 19.3 lists pathologic and iatrogenic causes of temporary (incident) and persistent wound pain (between dressing changes, at night, and at rest).[43]

Box 19.3 Etiology of Wound Pain

Pathologic

- Direct tumor compression of an organ
- Dermal erosion and exposure of nerve endings
- Damage of nerves related to direct tumor invasion or compression
- Edema secondary to impaired lymphatic or drainage, or wound infection
- Inflammation secondary to wound infection

Iatrogenic

- Manipulation of dressings
- Inappropriate dressing selection
- Adhesives
- Wound cleansing or irrigation
- Debridement

Source: Adapted from Reference 44: Woo K, Sibbald G, Fogh K, et al. Assessment and management of persistent (chronic) and total wound pain. *Int Wound J*. 2008;5(2):205–215; Reference 45: Probst S. Evidence-based management of fungating wounds. *Wounds* (Palliative Wound Care Supplement), 2010; and Reference 46: Price P, Fogh K, Glynn C, et al. Managing painful chronic wounds: the wound pain management model. *Int Wound J*. 2007;4(Suppl 1):4–15.

Box 19.4 Total Pain Management

Total pain origin

- Physical factors
  - Malignancy or underlying disease-specific pain
    - Somatic, neuropathic, or mixed
  - Wound pain
    - Somatic, neuropathic, or mixed
  - Wound care
    - Vigorous irrigation or rubbing of fragile tissue with cleansing
    - Frequent dressing manipulation and changes
    - Adherence of dressings to the wound bed during dressing removal
    - Painful wound bed
    - Infection
    - Medical adhesive-related skin injury
- Psychological and social factors
  - Housing, food, fiduciary insecurities
  - Anxiety, depression, grief, and prebereavement issues
  - Body image disturbances
- Spiritual factors
  - Existential angst

Interventions and referrals

- Long-acting opioids, short-acting breakthrough opioids, adjuvant pharmacologic and nonpharmacological interventions per nurse practitioner or hospice medical director
- Gentle irrigation, patting or blotting of wound bed
- Decrease number of changes with moisture-retentive dressings
- Soaking dressing before removal with normal saline (NS) or tepid tap water
- Nonadherent dressings: foams, petrolatum-based, silicone
- Topical opioids (10 mg morphine in 8 g hydrogel)[48]
- Topical anesthetics (2% lidocaine jelly 3–5 minutes before wound care)[48]
- Antimicrobial dressings and/or systemic antibiotics
- Use of burn net or garments, such as postsurgical bras, Lycra, or Attends undergarments to secure dressings and normalize body image (see Figure 19.1)
- If adhesives are necessary use skin protectants and apply paper tape
- Referral to social work, grief counselor
- Referral to spiritual care

Source: Adapted from Reference 48: Walsh A, Bradley M, Cavallito K. Management of fungating tumors and pressure ulcers in a patient with stage IV cutaneous malignant melanoma. *J Hosp Palliat Nurs*. 2014;16(4):208–214.

Comprehensive pain assessment is guided by the *total pain* concept, which includes physical, psychological, spiritual, and social factors.[47] A valid and reliable pain assessment tool is recommended, as is inclusion of both wound- and non–wound-related pain or discomfort and exploration of temporary and persistent wound pain etiologies. The total pain approach (see Box 19.4) includes advanced symptom management for malignancy or underlying disease-related pain, interprofessional involvement to address psychosocial or spiritual factors, and specialist-level wound care for local discomfort.[48]

Pruritus: The etiology of wound-related pruritus may be either pruritoceptive (cutaneous) or neuropathic (afferent neuronal pathways).[49] Wound-related pruritus has been reported in venous ulcers, burns, MFWs, pressure ulcers, and postsurgical wounds.[49] Itching may be part of the normal healing process[50] or due to inflammation, dryness, nerve regeneration,[51] exudate,[52] compression garments,[53] or dressings. Periwound moisture-associated dermatitis may also contribute to both pruritus and pain.[54] Periwound moisture-associated dermatitis is defined as inflammation and erosion of skin caused by prolonged exposure to wound effluent.[54] The principles behind the treatment of wound-related pruritus are similar to that of pain. The practitioner must first identify the underlying cause of the pruritus, if possible. Once the etiology has been addressed, a multifaceted approach to symptom management is recommended, combining systemic pharmacologic agents with topical therapies. Table 19.2 demonstrates periwound skin management options.

Infection, odor, and exudate: Infection may retard wound healing and contribute to odor, exudate formation, and pain.[18] Devitalized tissue enhances bioburden proliferation, contributes to malodor and excessive exudate, and is an impediment to wound healing.[55] Whenever possible, infections should be eliminated and necrotic tissue should be removed, two of the four key components of wound bed preparation[56,57] (see Box 19.5).

The degree of aggressiveness in managing infection and the removal of devitalized tissue is guided by the patient's advance directives and preferences. Wound infections at end of life may be treated empirically, by either oral or parenteral route, with or without concurrent topical antimicrobials, and rarely require cultures. Clinical diagnosis of infection in chronic wounds is more important than qualitative cultures.[58] Surface cultures are controversial and deep tissue cultures are rarely appropriate in palliative wound care.[58] The choice of wound debridement method depends on many factors, as shown in Box 19.6.

Table 19.3 summarizes the common debridement methodologies used in palliative wound care, the advantages and disadvantages of each, and contraindications. Mechanical debridement (wet-to-dry) is nonselective, painful, and labor-intensive and is not recommended in palliative patients.

Odor has been described as one of the most distressing symptoms to people with chronic wounds.[59] The source of the malodor may be related to moist necrotic tissue, bioburden, infection, unchanged or saturated dressings, or old dressings that have not been properly disposed of. The prevalence of malodor in MFWs is reported as 10.4%.[41] "Garbage," "rotting flesh," "putrid," and "moldy" are descriptors elicited from patients, family members, and other caregivers, including nurses.[60–62] One subject likened the smell to a "cadaver."[60] Malodor is pervasive; caregivers recall altering their

Table 19.2. Periwound skin management options

Skin protectant	Description	Consideration	Examples
Liquid polymer acrylates	Liquid polymers that contain solvents that when they evaporate, form a protective film	Periwound maceration Protection Preparation of skin attachment sites for drainage tubes, external catheters, surrounding ostomy sites, and adhesive dressings	Cavilon (3M) No-sting Skin Prep (Smith & Nephew)
Dimethicone	Silicone-based oil	Modest maceration Protection Good skin hydration Variable periwound skin irritant protection	Remedy Olivamine Dimethicone Moisture Barrier (Medline)
Zinc oxide-based skin protectant	White powder mixed with a cream or ointment base	Periwound skin irritant Protection Incontinence barrier Calazime contains menthol, which cools irritated skin Zinc offers poor skin hydration and does not avoid maceration Messy, difficult to remove Interferes with dressing adhesion and absorption	Remedy Phytoplex Z-Guard Skin Protectant Paste (Medline) Remedy Olivamine Calazime Skin Protectant Paste (Medline) Critic-Aid thick Moisture Barrier Skin Paste (Coloplast)
Petrolatum-based skin protectant	Blend of castor seed oil and hydrogenated castor oil	Periwound skin irritant and maceration Modest skin hydration Incontinence barrier Messy, difficult to remove Interferes with dressing adhesion and absorption	ConvaTec Sensi-Care Protective Barrier (ConvaTec) Remedy Phytoplex Z-Guard Skin Protectant Paste (Medline)

Source: Reprinted with permission from Reference 10: Tilley, C, Lipson, J, Ramos, M. Palliative wound care for malignant fungating wounds: Holistic considerations at end of life. *Nurs Clin North Am*. 2016;48(3):479–501.

breathing patterns to avoid the smell and having vivid memories decades later.[62]

Multiple studies have documented the detrimental role malodor has had on body image,[61,63,66,67] relationships,[61,62,67] and sexuality and femininity,[61,63,66] resulting in shame, embarrassment, anxiety, and lack of self-confidence,[61–67] leading to social isolation[61,63,64,66,67] and diminished QOL.[58,61]

Prevalence of exudate in MFWs was reported at 14.6%[60] and identified as one of the most challenging symptoms to manage, seriously impacting psychosocial function[60,61,63,64,66] and contributing to the development of periwound moisture-associated dermatitis.[66] Losing the physical boundaries of their skin, with wounds described as "festering like a running nose,"[60] participants described being humiliated and exhausted by the wounds, and the frequent dressing changes and cleaning of soiled clothing becoming all-consuming.[60,63] Public soiling of their clothing also forced the women into self-imposed isolation, "safe from scrutiny and negative comments that damaged their identity."[66] Management of odor and exudate may be difficult, requiring WOC nurse consultation. Table 19.4 displays the dressings and antibacterial agents to manage infection and control odor and drainage.

Bleeding: Bleeding may range from superficial, isolated rupture of microvasculature in the wound bed to erosion of large vessels and hemorrhage. Disruption of blood vessels, either by direct tumor invasion or friable wound beds with excessive bioburden, was described by patients as "unpredictable."[68] One woman recalled spontaneous bleeding during a work meeting, the blood camouflaged by her jacket, necessitating an impromptu clothing change.[66] Uncontrolled bleeding was so severe at times that it forced women, experiencing disbelief and shame, to seek the medical care they had been avoiding.[64] Table 19.5 outlines interventions for bleeding.

Goals of care discussions surrounding bleeding are an integral part of advance care planning for the hospice patient with a complex, nonhealing wound because interventions may range from the benign (i.e., direct pressure, vitamin K replacement,

Box 19.5 Key Components to Wound Bed Preparation: TIME

Tissue that is nonviable must be debrided.
Infection (or inflammation) must be reduced and managed.
Moisture imbalance or exudate control must be addressed to avoid desiccation or maceration.
Epidermal margins of the wound must be examined for nonadherence.

modification of topical antimicrobial therapy) to aggressive and/or invasive (i.e., vascular interventions for hemorrhage, blood products, radiation). The discontinuation of anticoagulation for patients with atrial fibrillation, deep vein thrombosis, pulmonary embolism, or embolic stroke requires a discussion of risks versus benefits (Figure 19.2).

Lymphedema: Lymphedema is known to have a negative psychological and social impact on patients.[70] Patients with lymphedema secondary to MFWs of the breast reported a sense of compromised normalcy. Restricted mobility limited wardrobe choices, as did the desire to "hide" the arm swelling due to embarrassment, ultimately restricting access to social support and contributing to isolation.[60] Chapter 18 provides in-depth information on lymphedema.

Box 19.6 Factors Influencing Choice of Wound Debridement Method

- Amount of debris
- Available time for debridement
- Cost of debridement process
- Nature of care setting
- Patient allergies
- Patient's pain level
- Patient's prognosis and treatment plan
- Patient's wishes and opinions
- Potential patient problems
- Maceration of wound
- Tissue trauma
- Bleeding (hemorrhage)
- Presence of infection
- Size of wound
- Skill of the clinician
- Type of debris
- Type of exudate
- Wound depth and undermining and tunneling

Source: Reprinted with permission Reference 55: from Beitz J. Wound debridement: Therapeutic options and care considerations. *Nurs Clin North Am*. 2005;40:233–246.

Bulk effect of wounds and dressings: Bulk effect of wounds and dressings refers to the profile of either the wound tissue itself or the contour of dressings and bandages against the normal planes of the body. This can impact clothing choices, restrict mobility, and result in additional symptoms such as discomfort or pruritus.[60] Conscious utilization of surgical bras (see Figure 19.1), burn net, and gender-specific absorptive undergarments to secure dressings may help reduce bulk effect.

Periwound Moisture-Associated Dermatitis

Periwound moisture-associated dermatitis is one of four subcategories included under the umbrella term moisture-associated skin damage (MASD) and is a key consideration in palliative wound care. Heavily exudating wounds may cause an overhydration of the skin and maceration, leading to further skin breakdown, infections, pain, or pruritus.[71] Maceration of the skin is described as irritation and damage of the skin adjacent (within a 4 cm periwound border) to a wound caused by supersaturation.[72] The bordering skin may present as maceration; pale, white, or gray wrinkled skin or inflammation; erythema; and swelling, usually associated with pain or pruritus.[71]

Composition of exudate, in addition to volume, has been shown to correlate with risk of developing MASD.[73,74] One study of women with fungating breast wounds found exudate with higher levels of putrescine and with the presence of cadaverine were associated with higher incidence of periwound moisture-associated dermatitis and pruritus.[75,76]

Treatment and prevention of pruritus caused by MASD starts with the selection of an appropriate absorbent dressing and cleansing of the wound bed. Periwound skin protection is the crucial next step in preventing MASD with several product options available (see Table 19.2).

No studies have specifically compared products used in periwound skin protection in patients with MFWs. A meta-analysis by Schuren and coworkers in nonmalignant wounds found film barrier to be superior to a placebo in four studies and no significant differences when compared with zinc oxide–based or petrolatum-based products.[77]

Hospice formularies may already include petrolatum, Calazime, and zinc oxide-based skin barriers as part of their incontinence protocols. A liquid-forming acrylate is also recommended because it does not interfere with adherence of dressings or pouching appliances and is used to protect the skin from MARSI[78] and to prevent or treat MASD.[54]

Multiple factors should be considered when selecting a skin barrier, including location, allergies, and caregiver support. A liquid polymer acrylate for upper body, head, and facial wounds is appropriate because there is less mess and no interference with adhesion of dressings.[10] Consider a zinc oxide–based or petrolatum-based skin barrier for genital or groin wounds, especially in the presence of fecal or urinary incontinence.[10]

Wound Assessment Principles

Wound assessment should be performed upon admission to a hospice or palliative care service, weekly thereafter, and with any change in condition. The use of a systematic approach with a comprehensive assessment tool is recommended (see Box 19.7). Monitoring of the wound by less-skilled caregivers with dressing changes is helpful, with the clinician reporting changes or

Table 19.3 Common debridement types and methodologies in palliative care

Method/Definition	Advantages	Disadvantages	Contraindications
Chemical (nonselective) Hypochlorites (e.g., Dakin's solution) Povidone iodine Cadexomer iodine (e.g., Iodosorb, Iodoflex)	Helps debride necrotic tissues slowly Lowers microbial count Cheap and readily available Broad-spectrum antimicrobial May help dry slough for easier debridement Slow release Safe for cellular viability Absorbs exudate Helps with autolytic debridement	Deleterious to healing tissue Possibly irritating to periwound skin Stains tissue Deleterious to fibroblasts Safe for fibroblasts Use with caution in patients with thyroid disease	Clean, noninfected wound Clean, noninfected wound Iodine allergy Clean, noninfected wound
Enzymatic (selective) Enzymes that work by degrading and debriding necrotic tissue by digesting and dissolving it	Good for patients who decline sharp debridement or surgery, or are on anticoagulants or home care Will not harm normal tissue Can be used in infected wounds, sometimes used with topical antibiotics Cost effective if used properly	Not effective for advanced cellulitic wounds Require prescriber's order Expensive Cannot be used with other common wound products such as metal ions (e.g., silver) or with topical antiseptics (e.g., Dakin's) Cross-hatching of eschar recommended	Clean, granulating wound Allergies
Autolytic (selective) Use of body's own wound fluid enzymes to liquefy necrotic tissue; fully or semi-occlusive moisture-retentive topical therapy. Hydrogels, alginates, foams, hydrofibers, films	Hydrogels, alginates, foams, and hydrofibers will absorb some wound fluid Maintain moist wound therapy Easy to perform in any care setting Comfortable and soothing Good choice if not a candidate for sharp debridement	Works slowly compared to other methods Requires constant monitoring for infection Hydrocolloid dressing fluid odor often mistaken for "infected" Absorptive dressings can dry out wound bed if not discontinued when appropriate	Dry wound beds are not appropriate for absorptive dressings
Conservative Sharp Debridement (selective) Use of instruments to remove necrotic tissue from wound bed	Fast and effective Can be performed at the bedside Preferred if debridement is urgent (sepsis) May be performed by specially educated nurses, therapists, and physicians	Analgesia required pre-procedure Require discernment of viable vs. nonviable tissue Potential for bacteremia Requires special training and/or licensure	Bleeding disorders Severe immune compromise Ischemic extremity

Source: Adapted from Reference 55: Beitz J. Wound debridement: Therapeutic options and care considerations. *Nurs Clin North Am*. 2005;40:233–246.

disconcerting findings to the registered nurse or advanced practice registered nurse.

Pressure Injuries and Medical Device Related Pressure Injuries

The NPUAP changed the term "pressure ulcer" to "pressure injury" (PI) in 2016 to lessen confusion over staging PIs with intact skin versus open ulcers.[26] A PI is localized damage to the skin and/or underlying soft tissue, usually over a bony prominence or related to a medical or other device.[26] PIs in palliative care settings are often not preventable, and interventions to eradicate them in the terminally ill are complicated by the population's frailty, extensive risk factors, and comorbid conditions.[18–21]

"Medical device–related pressure injury" describes an etiology of PI and should be staged using the same pressure injury staging system (see Table 19.6). These injuries are caused by prolonged pressure from diagnostic (temperature-sensing Foley catheters) or therapeutic (nasogastric tubes, rectal tubes) devices and usually result in an injury that conforms to the shape of the device.[26]

Risk Factors, Risk Assessment, and Risk Reduction

A variety of factors exist in those with advanced and terminal illness that put them at risk for PI development and nonhealing. Risk factors include advanced age, protein-calorie malnutrition, immobility and inactivity, shear, friction, moisture, incontinence, and altered sensory perception.[80,85] Screening tools ascertain patients at risk for PI development through identification of specific risk factors, which then allows for targeted risk-reduction interventions. The NPUAP has recommended assessing the risk for new PI development on admission, at regular intervals

Table 19.4 Dressings and antibacterial agents to control odor and drainage

Dressings and antibacterial agents examples	Examples of brands	Beneficial effects and considerations	Cost
Foams	Allevyn (Smith & Nephew) Aquacel Foam (Convatec) Tegaderm Foam (3M) Mepilex (Monlynlycke Health Care)	Promotes moist wound environment and does not adhere to tissue. Prevents strikethrough. Multiple shapes and sizes available to fit difficult dressing sites (i.e., heels) and conforms to the body.	5 × 5 box = $$ 5 × 5 box = $$ 6 × 6 box = $$ 6 × 6 box = $$
Calcium alginates	Algicell (Derma Sciences) Algisite M (Smith & Nephew) Tegaderm High Gelling (3M)	May be used to cover or fill wound bed. Dressing material becomes a gel and absorbs any drainage while promoting a moist wound bed. May act as a hemostatic agent.	4 × 4 box = $ 4 × 4 box = $ 4 × 4 box = $
Honey	Activon Tulle (Avancis) Medihoney (Medihoney)	Supersaturated sugar solution with high osmolarity, low water activity. Bactericidal, moistens wound and removes necrotic tissue. Lowers wound pH to promote healing.	4 × 4 box = $ 4 × 4 box = $
Silver	Aquacel Ag hydrofiber (Convatec) Acticoat 3 (Smith & Nephew) Optifoam Ag (Medline)	Gradual release of silver provides sustained broad-spectrum bactericidal effects.	12 box = $$$ 4 × 4 box = $$$ 4 × 4 box = $$
Charcoal	CarboFlex (Convatec)	Absorbs small gas molecules and bacterial spores. Used as either primary or secondary dressings	4 × 4 box = $$
Dakin Solution	0.25% Concentration	Broad-spectrum bactericidal effects, promotes dissolution of necrotic tissue. May require twice-daily dressing changes	1 16-oz bottle = $
Metronidazole	1% Flagyl spray 5% Flagyl powder Crushed tablets 0.71% Flagyl gel	Bactericidal, effective against anaerobes	100 mL = $ 57 g = $ 14 tablets = $ 71% gel (1 tube,45 g) = $$

Prices: $, <$100; $$, >$100; $$$, >$200.

Data from References 10, 15, 36, 37, and prices from Wound Care Shop. http://www.woundcareshop.com/. Accessed October 12, 2017.

Source: Reprinted with permission from Tilley C, Lipson J, Ramos M. Palliative wound care for malignant fungating wounds: Holistic considerations at end of life. *Nurs Clin North Am*. 2016;48(3):479–501.

thereafter, and with any change in condition using a validated risk assessment tool.[80,85] Multiple PI risk assessment tools have been developed. The Norton Scale[81] and the Braden Scale[82] are two of the most widely used tools, despite minimal data on their validation in hospice populations. The Hunters Hill Marie Curie Center Risk Assessment Tool[83] and the Hospice Pressure Ulcer Risk Assessment Scale[84] were specifically developed for and validated in hospice populations. A comparison of these 4 scales is shown in Table 19.7.

Risk reduction interventions include pressure redistribution, skin and incontinence care, and maximizing nutrition and hydration.[80,85] Avoid foam rings, foam cut-outs, or donut-type devices because they concentrate pressure on the surrounding tissue.[85] Table 19.8 summarizes select recommendations from the *WOCN 2016 Guideline for Prevention and Management of Pressure Injuries (Ulcers)* for preventing PIs[85] and palliative care-specific considerations or adaptions. The patient at end of life may not tolerate all recommendations due to symptoms of pain, dyspnea,

Table 19.5 Interventions for wound-related bleeding

Category of bleeding	Interventions	Considerations
Prevention	Dressing selection and wound cleansing	1. Nonadherent dressings are recommended as a contact layer (silicone, foam, or petrolatum-based gauze) 2. Gentle cleansing or irrigation 3. Wet dressings before removal to loosen and prevent adherence to the wound bed
Minor bleeding (controllable at the bedside)	Direct pressure Silver nitrate Epinephrine soaks Calcium alginate	1. Apply local pressure with clean gauze 2. See Figure 19.2 3. Soak gauze with 1mg of epinephrine and 1ml of NS (1:1 ratio) applied for 10 minutes of direct pressure to promote local vasoconstriction [10]
Major bleeding (requiring invasive or aggressive interventions)	Vascular intervention Radiation	1. If using as a hemostatic agent, may embed itself in the wound and be difficult to extract
Hemorrhage as a terminal event	Comfort measures	1. Dark towels should be readily available and used to contain and absorb blood loss 2. Sedate with a benzodiazepine and manage pain with an opioid 3. Cover with blankets because blood loss may lead to hypothermia and cause chills or rigors

Source: Reprinted with permission from Tilley, C, Lipson, J, Ramos, M. Palliative wound care for malignant fungating wounds: Holistic considerations at end of life. *Nurs Clin North Am.* 2016;48(3):479–501.

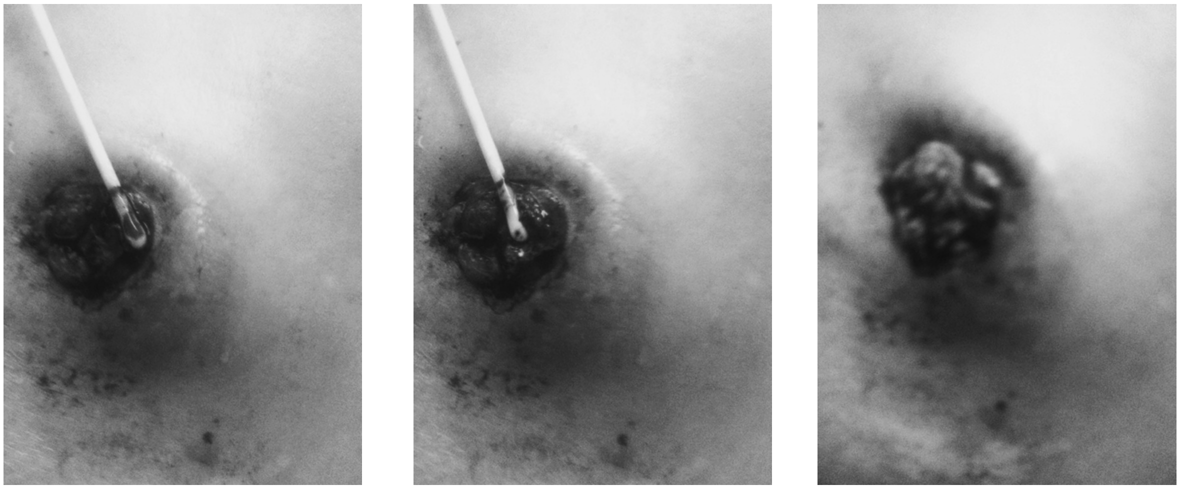


Figure 19.2 Cauterization of bleeding abdominal malignant lesion with silver nitrate sticks. Note the stick is rolled over the bleeder, causing a pearly gray appearance to the tissue. This may be repeated with each dressing change at bedside, is relatively inexpensive, and is easy to learn. Assess for stinging or burning, and, if uncomfortable, consider alternatives.

Source: Reference 19.

Box 19.7 Systematic Wound Assessment

1. Etiology/type of skin damage
2. Location
3. Stage (PIs only)
4. Dimensions: (length [head-to-toe], width [hip-to-hip], depth [use a q-tip], height)
5. Undermining/Tunneling (Stage III or IV pressure injuries [PIs] only)
   Measure undermining clockwise, then the deepest part of the undermining
   Measure depth of sinus tract/tunnel and give direction by the clock method
6. Wound Base Description
   Granulation: Pink or beefy red, shiny, moist, granular
   Necrotic Tissue: Gray to black and moist
   Eschar: Gray to black and dry/leathery
   Slough: Yellow to white and may be stringy (loose) or appear as a layer over the wound base (adherent)
   Epithelial: New or pink shiny tissue
   May be mixed so approximate in percentages
7. Drainage
   Amount: scant, moderate, or copious
   Color/Consistency: Serous, serosanguineous, purulent, or other
8. Odor: Present or not
9. Periwound skin
10. Pain
    Associated with the wound dressing removal, cleansing, debriding, or dressing application
11. Infection
    Yes or no. Describe signs or symptoms

Source: Adapted from Reference 10: Tilley C, Lipson, J, Ramos, M. Palliative wound care for malignant wounds at end-of-life. *Nurs Clin North Am*. 2016;48:479–501.

delirium, or terminal secretions, or may make the conscious choice not to participate based on his or her goals of care and advance directives. The patient's and family's wishes and preferences at end of life must be respected and documented in the patient's medical record and plan of care.

Treatment

Palliative wound care is an emerging field of research. Currently, there are no evidence-based protocols for treating PIs in the terminally ill and dying.[86] Seven principles for the palliative management of wounds in the terminally ill have been proposed: preventing wound development and/or deterioration, correcting or treating the underlying cause of the wound, controlling wound-related symptoms, using patient self-assessment, providing psychosocial support, promoting independence, and improving QOL.[87]

Palliative wound care combines the advanced symptom management previously discussed in this chapter with evidence-based interventions. Again, the patient's and family's wishes and preferences drive the plan of care. Table 19.9 summarizes select evidence-based treatment recommendations from the *WOCN 2016 Guideline for Prevention and Management of Pressure Injuries (Ulcers)* for the treatment of PIs[85] and palliative care-specific considerations or adaptions. Comfort is of the utmost importance and may supersede wound care for those who are actively dying or have a condition causing them to have a single position of comfort.[59]

Skin Tears and Medical Adhesive-Related Skin Injury

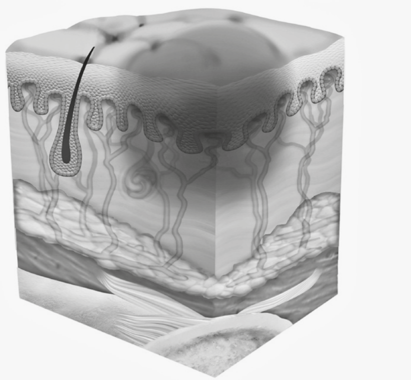
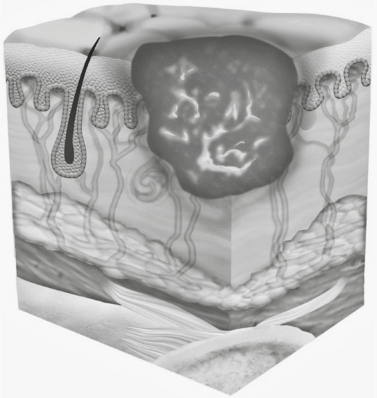
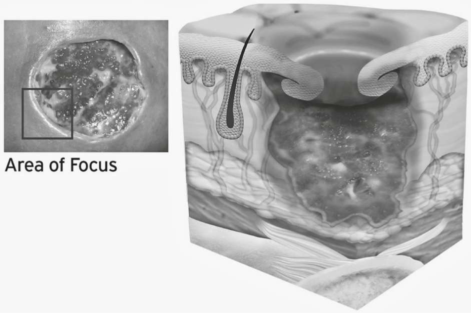
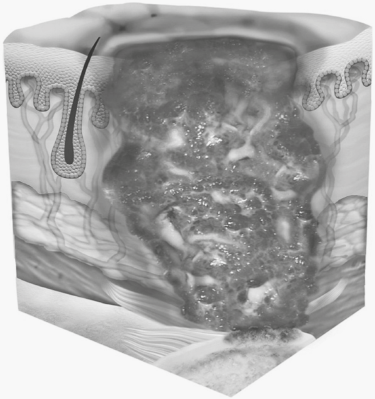
Skin tears are wounds caused by shear, friction, and/or blunt force trauma resulting in separation of skin layers.[88,89] A skin tear can be partial thickness (separation of the epidermis from the dermis) or full-thickness (separation of both the epidermis and dermis from underlying structures).[88] Skin tears may increase patient morbidity and mortality[88,89] and are associated with increased pain and decreased QOL.[90] There are three classification systems for skin tears: the original 1993 Payne-Martin classification tool,[91] the 2007 Skin Tear Audit Research (STAR) classification system,[92] and, most recently, the 2013 International Skin Tear Advisory Panel (ISTAP) Skin Tear classification system displayed in Figure 19.3.[90] Skin tears are a subset of MARSI, but have varied etiologies.[78] Few studies have evaluated the prevalence of skin tears, and none have exclusively studied this phenomenon in hospice and palliative care populations. A 2017 systematic review reported prevalence of skin tears to be between 3.3% and 22% in the acute care setting and between 5.5% and 19.5% in the community setting.[93] Long-term care studies have reported skin tear prevalence to be between 2.23% and 92%.[96]

A MARSI is an occurrence in which erythema and/or other manifestation of cutaneous abnormality (including, but not limited to, vesicle, bulla, erosion, or tear) persists 30 minutes or more after removal of the adhesive.[94] Types of MARSI by etiology include (mechanical) epidermal stripping, tension injury or blister, skin tear (dermatitis), irritant contact dermatitis, allergic dermatitis, (moisture) maceration, and (inflammatory) folliculitis.[94] MARSI prevalence is largely unknown, with no studies reporting the prevalence in hospice and palliative care populations. Limited studies have found daily subject prevalence to be from 3.4% to 25% in acute care,[94] a cumulative incidence of 15.5% in long-term care,[95] and MARSI to be the primary cause of skin breakdown in 2,820 neonatal intensive care unit patients.[96]

Risk Factors and Prevention

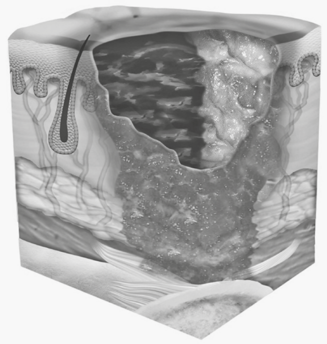
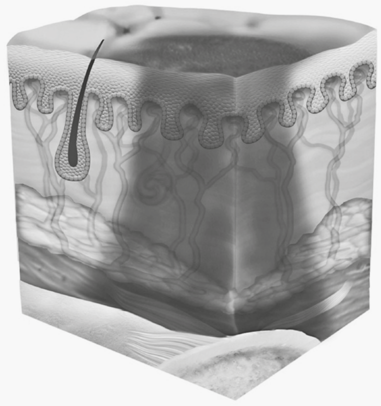
Patients with advanced illness, including those at end of life, are most at risk for skin tears and MARSI. Factors that increase the risk for both types of injury are similar. Intrinsic factors include extremes of age, race/ethnicity, dermatologic conditions (eczema, dermatitis), underlying medical conditions (e.g., diabetes, infection, immunosuppression), malnutrition, and dehydration.[78,88] Extrinsic factors include repeated taping, tape/dressing/

Table 19.6 NPUAP pressure injury staging system

Stage	Definition and clinical description	Illustration
Stage 1 Pressure Injury: Non-blanchable erythema of intact skin	Intact skin with a localized area of nonblanchable erythema, which may appear differently in darkly pigmented skin. Changes in sensation, temperature, or firmness may precede the presence of blanchable erythema. Color changes do not include purple or maroon discoloration; these may indicate deep tissue pressure injury.	
Stage 2 Pressure Injury: Partial-thickness skin loss with exposed dermis	Partial-thickness skin loss with exposed dermis. The wound bed is viable, pink or red, moist, and may also present as an intact or serum-filled blister. Adipose and deeper tissues are not visible and granulation tissue, eschar and slough are not present. These injuries commonly result from adverse microclimate and shear in the skin over the pelvis and shear in the heel. This stage should not be used to describe moisture associated skin damage (MASD) including incontinence associated dermatitis (IAD), intertriginous dermatitis (ITD), medical adhesive related skin injury (MARSI), or traumatic wounds (skin tears, burns, abrasions).	
Stage 3 Pressure Injury: Full-thickness skin loss	Full-thickness loss of skin, in which adipose is visible in the ulcer and granulation tissue and epibole (rolled wound edges) are often present. The depth of tissue damage varies by anatomical location; areas of significant adiposity can develop deep wounds. Slough and/or eschar may be visible, and undermining,[a] tunneling,[b] or sinus tracts[c] may occur. Fascia, muscle, tendon, ligament, cartilage and/or bone are not exposed.	
Stage 4 Pressure Injury: Full-thickness skin and tissue loss	Full-thickness skin and tissue loss with exposed or directly palpable fascia, muscle, tendon, ligament, cartilage or bone in the ulcer. The depth of tissue damage varies by anatomical location. Slough and/or eschar may be visible, and epibole, undermining,[a] tunneling,[b] or sinus tracts[c] may occur.	

(*continued*)

Table 19.6 Continued

Stage	Definition and clinical description	Illustration
Unstageable Pressure Injury: Obscured full-thickness skin and tissue loss	Full-thickness skin and tissue loss in which the extent of tissue damage within the ulcer cannot be confirmed because it is obscured by slough or eschar. If slough or eschar is removed, a Stage 3 or Stage 4 pressure injury will be revealed.	
Deep Tissue Pressure Injury: Persistent non-blanchable deep red, maroon or purple discoloration	Intact or non-intact skin with localized area of persistent non-blanchable deep red, maroon, purple discoloration or epidermal separation revealing a dark wound bed or blood filled blister. Pain and temperature change often precede skin color changes. Discoloration may appear differently in darkly pigmented skin. This injury results from intense and/or prolonged pressure and shear forces at the bone-muscle interface. The wound may evolve rapidly to reveal the actual extent of tissue injury, or may resolve without tissue loss.	

[a] Undermining: Deep tissue (subcutaneous fat and muscle) damage around the wound margin.

[b] Tunneling: Tunnel under the skin surface that doesn't involve deep tissue.

[c] Sinus tracts: A narrow tract that moves away from the wound margins and downward into the wound.

Source: Adapted with permission National Pressure Ulcer Advisory Panel (2016), http://www.npuap.org/resources/educational-and-clinical-resources/npuap-pressure-injury-stages/ (accessed November 3, 2017) and National Pressure Ulcer Advisory Panel. Pressure injury staging illustrations 2016. http://www.npuap.org/resources/educational-and-clinical-resources/pressure- injury-staging-illustrations/ (accessed December 18, 2017).[79]

Table 19.7 Pressure injury risk assessment tools

Pressure injury risk assessment tool	Year developed	Subscales	Validation in hospice & palliative populations
Norton Scale	1958	Physical condition, mental state, activity, mobility, incontinence	Minimal information on the validation in hospice patients[81]
Braden Scale	1983	Sensory perception, moisture, activity, nutrition, friction/ shear, mobility	Minimal information on the validation in hospice patients[82] Braden scores are highly correlated with Karnofsky and Palliative Performance Scale scores
Hunters Hill Marie Curie Center Risk Assessment Tool	2000	Sensation, mobility, moisture, activity in bed, nutrition/weight change, skin condition, friction/shear	Developed specifically for palliative care and validated in hospice patients[83]
Hospice Pressure Ulcer Risk Assessment Scale	2003	Physical activity, mobility, age	Developed specifically for palliative care and validated in hospice patients[84]

Table 19.8 Risk factors for pressure injuries and risk reduction strategies in palliative care

Risk factor	Risk reduction intervention	Palliative considerations
Pressure & Immobility	1. Minimize/eliminate pressure from medical devices 2. Schedule regular repositioning and turning for bed-bound and chair bound patients 3. Use heel suspension devices and protective dressings in at-risk patients 4. Utilize support surfaces on beds and chairs to redistribute pressure. 5. Place patients at high risk on pressure redistribution surfaces. 6. Educate patients and caregivers about the causes and risk factors for developing PIs and ways to minimize the risks	1. Equipment such as Bi-PAP masks and oxygen tubing may need protective hydrocolloid over the bridge of the nose or padding over the ears 2. Assess and premedicate for pain 20–30 minutes prior to care, patients with uncontrolled symptoms may not tolerate repositioning 3. Introduce the possibility of unavoidable pressure ulcers due to skin failure, assure the family it is not from poor care
Friction/Shear	1. Maintain the HOB elevation at/or below 30 degrees 2. Use a 30-degree side-lying position	1. Patient with increased intracranial pressure, ascites, end-stage pulmonary or cardiac disease, or orthopnea may not tolerate 2. May facilitate drainage of secretions
Incontinence	Use incontinence skin barriers to protect and maintain intact skin	Consider Foley placement for those with dyspnea or pain who cannot tolerate frequent skin care
Nutrition	Offer individuals with nutritional and pressure ulcer risks a minimum of 30–35 kcal/kg body weight per day, 1.25–1.5g of protein/kg body weight per day, and 1mL of fluid intake per kilocalorie per day	The patient with advanced disease or who is at end of life may not realistically tolerate these nutritional recommendations. Dysphagia, odynophagia, anorexia-cachexia syndromes, advanced symptoms or voluntarily stopping eating and drinking will warrant an individualized plan of care

Source: Adapted from Reference 87: Wound, Ostomy and Continence Nurses Society-Wound Guidelines Task Force. WOCN 2016 guideline for prevention and management of pressure injuries (ulcers). *J Wound Ostomy Continence Nurs.* 2017;41(3):238–243.

Table 19.9 Palliative considerations in the treatment of pressure injuries

Treatment	Palliative considerations
1. Float the heels completely off the surface with a pillow for stage I or II PIs or a heel suspension device for Stage III or IV PIs.	1. Assess patients for uncontrolled symptoms, especially pain, prior to heel suspension and premedicate 20–30 minutes prior if needed. Patients at end of life may not tolerate heel suspension, follow individual preferences.
2. Turn and reposition the patient regularly and frequently.	2. Assess patients for uncontrolled symptoms, especially pain and dyspnea prior to turning and premedicate 20–30 minutes prior if needed. Patients at end of life may not tolerate frequent repositioning, so develop a flexible schedule and follow individual preferences, including their "position of comfort."
3. Utilize support surfaces for patients with pressure injuries that meet the individual's needs and are compatible with the care setting (both seating and lying redistribution).	3. Consider changing the support surface to improve pressure redistribution and comfort.
4. Utilize an individualized bowel/bladder management program for the patient with incontinence.	4. Foley catheters may be preferred to manage urinary incontinence in patients who cannot tolerate toileting due to advanced symptoms (pain, dyspnea).
5. Cleanse the wound and periwound at each dressing change with potable tap water, distilled water, wound cleanser or normal saline.	5. Use care to remove devitalized tissue to control wound odor.
6. Consider a 2-week course of topical antibiotics for nonhealing, clean PIs.	6. Review the patient's advance directives to discern their willingness to trial antibiotics.
7. Consider the use of topical antiseptics for "maintenance wounds," which are defined as wounds not expected to heal for wounds that are critically colonized.	7. Dakin solution may sting in the wound and can be irritating to the respiratory system.
8. Use systematic antibiotics in the presence of bacteremia, sepsis, advancing cellulitis, or osteomyelitis.	8. Review the patient's advance directives to discern their willingness to trial antibiotics.
9. Debride the PI of devitalized tissue.	9. Review the patient's advance directives and goals of care. Avoid sharp debridement with fragile tissue that bleeds easily.
10. Implement appropriate treatment of PIs to optimize healing, recognizing that complete healing may be unrealistic in some patients.	10. Use dressings that can remain in place for longer periods of time to promote comfort.
11. Offer individuals with nutritional and pressure ulcer risks a minimum of 30–35 kcal/kg body weight per day, 1.25–1.5 g of protein/kg body weight per day, and 1mL of fluid intake per kilocalorie per day	11. Allow the patient to ingest fluids and foods of choice. Offer several small meals per day. Adequate nutrition is often not attainable when the patient is unable or declines to eat.

Source: Adapted Reference 87: from Wound, Ostomy and Continence Nurses Society-Wound Guidelines Task Force. WOCN 2016 guideline for prevention and management of pressure injuries (ulcers). *J Wound Ostomy Continence Nurs.* 2017;41(3):238–243; and Reference 59: Langemo DK, Black J. National Pressure Ulcer Advisory Panel. Pressure ulcers in individuals receiving palliative care: A national pressure ulcer advisory panel white paper. *Adv Skin Wound Care*. 2010;23(2):56–69.

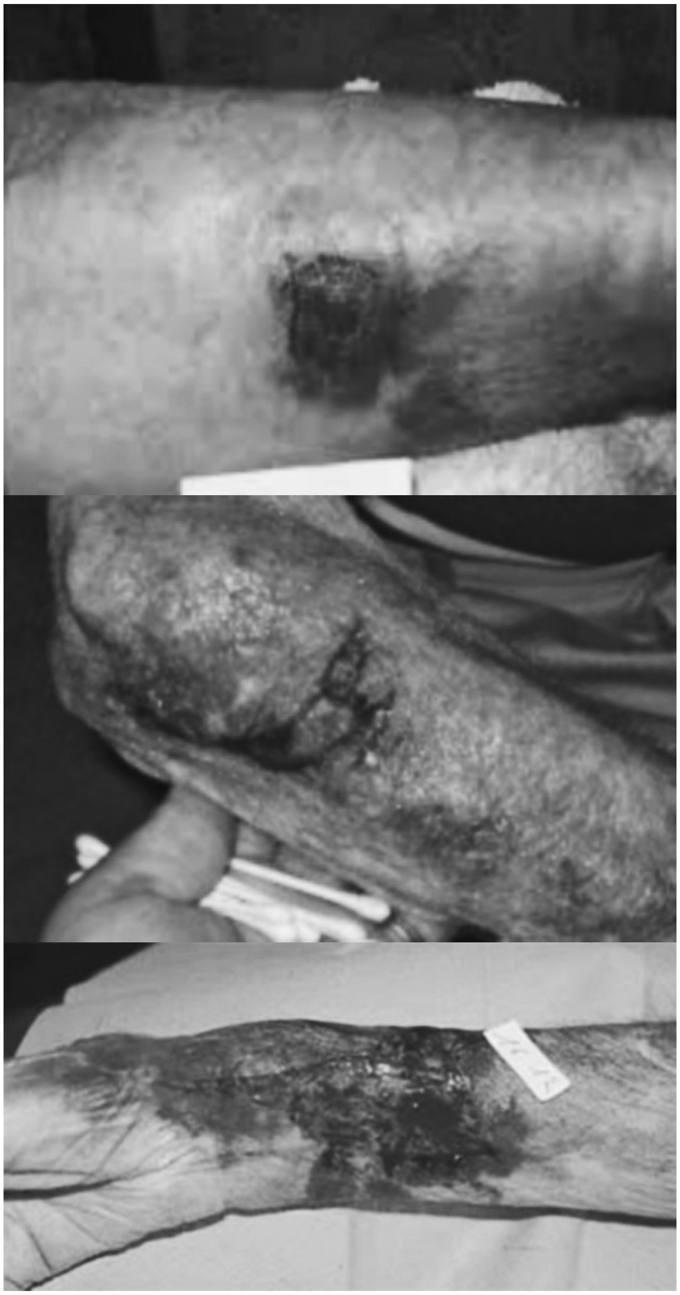


Figure 19.3 ISTAP Skin Tear Classification System:
Type I: No skin loss
Type II: Partial flap loss
Type III: Total flap loss

device removal, photodamage, radiation therapy, maceration, certain medications (long-term corticosteroids, anticoagulants), and drying of the skin due to harsh skin cleansers or excessive bathing.[88,93] Falls, previous skin tears, the presence of edema, and handling during care are additional risk factors that contribute to skin tears.[88,93] Not all skin tears are preventable in high-risk patients (multiple comorbidities, multiorgan failure, dementia with aggression), and incurring this type of wound does not necessarily imply poor quality of care.[78] Table 19.10 shows interventions to prevent skin tears and MARSI. In addition to the interventions listed in Table 19.10, the ISTAP maintains that it is essential to incorporate fall prevention as part of skin tear prevention programs.[90]

Treatment

The best management for both skin tears and MARSI is prevention. When these wounds do occur, it is generally recommended that the practitioner follow evidence-based wound care principles and consult a wound specialist if the wound doesn't heal within 7 days or deteriorates.[97,98] A dressing should be chosen that (1) maintains constant moisture, (2) suits the local wound environment, (3) protects the periwound skin, (4) controls or manages exudate, (5) controls or manages infection, and (6) optimizes caregiver time.[97,98] Adhesive strips, hydrocolloids, and traditional films are not recommended for either injury.[97,98] Best practices in skin tear management include (1) cleansing with a nontoxic solution, such as normal saline; (2) approximate the skin flap (if possible); (3) control bleeding and remove clots; (4) apply a skin protectant periwound; and (5) apply a hydrogel, alginate, foam, soft silicone, or nonadherent dressing.[97,98] These best practices may be considered in the care of MARSI as well. Never secure dressings covering either type of wound with adhesive products; instead utilize burn net, stocking-like products, or cotton gauze wraps.

Chronic Critical Limb Ischemia with Gangrene

Chronic critical limb ischemia (CCLI) is a condition related to arterial occlusive disease that manifests as rest pain, ulceration, or gangrene.[99] Wound healing is usually not a realistic goal when invasive vascular interventions are not feasible. Palliative wound care goals often include delaying an inevitable amputation.[100] Gangrene is the localized death and decomposition of body tissue, resulting from either obstructed circulation or bacterial infection and may be classified as either dry or wet.[100] Dry gangrene develops slowly, with a line of demarcation between viable and gangrenous tissue and ischemic pain during early development.[101] As the limb or digit mummifies, the gangrenous appendage becomes painless.[101] Dry gangrene is usually odorless and may be painted with povidone iodine every 48 hours and wrapped with a dry gauze dressing, with caution not to moisten the necrotic tissue to prevent conversion to wet gangrene. Cadexomer iodine was also shown to be an effective palliative dressing in a retrospective study of 11 patients on the antimicrobial effect of iodine preventing wet gangrene.[100]

Wet gangrene signals bacterial infection which can spread quickly to other tissues, causing pain and fevers.[101] The tissue becomes discolored, boggy, blistered, and malodorous with exudate. *Clostridium perfringens* is a gas-forming organism with an affinity for necrotic tissue that may cause crepitus in the affected limb.[101] Half- or quarter-strength Dakin solution once or twice daily has been used successfully to manage odor and exudate due to its broad-spectrum bactericidal properties. Dakin solution has been shown to be effective against *C. perfringens*, aerobes, anaerobes, biofilms, and multidrug-resistant organisms.[102] Anecdotally, Dakin solution also has desiccant properties, drying the wound bed and thereby decreasing exudate.

Malignant Fungating Wounds

In 2018, there will be an estimated 1,705,347 new cancer cases diagnosed and 575,610 cancer deaths in the United States.[103] MFWs are nonhealing wounds resulting from aggressive

Table 19.10 Preventing skin tears and medical adhesive–related skin injuries (MARSI)

Skin tears	MARSI
1. Assess for risk upon admission to healthcare service and whenever the individual's condition changes 2. Implement a systematic prevention protocol 3. Have individuals at risk wear long sleeves, long pants/trousers, or knee-high socks 4. Provide shin guards to those individuals who experience repeated skin tears to shins 5. Ensure safe patient handling techniques and equipment/environment 6. Involve individuals and families in preventive strategies 7. Educate registered and nonregistered staff and caregivers to ensure proper techniques for providing care without causing skin tears 8. Consult dietitian to ensure adequate nutrition and hydration 9. Keep skin well-lubricated by applying hypoallergenic moisturizer at least 2 times per day 10. Protect individuals at high risk from trauma during routine care and from self-injury	1. Application of adhesive-containing products ◆ Ensure the area is clean and dry ◆ Clip excessive hair ◆ Apply a skin barrier ◆ Allow skin prep to thoroughly dry ◆ Apply the adhesive product without tension, pulling, or stretching ◆ Smooth the adhesive product into place ◆ Use gentle, stretchable adhesive products if edema/movement anticipated ◆ If compression needed, stretch the adhesive over the dressing only and press remaining tape onto skin without tension 2. Removal of adhesive-containing products ◆ Loosen edges of the adhesive product ◆ With the fingers of the opposite hand, push the skin down and away from the adhesive ◆ Remove the adhesive product low and slow in the direction of hair growth ◆ Use the stretch and relax technique to remove transparent films ◆ Slowly remove tape strips by each side, towards the wound ◆ Use medical adhesive remover

Source: Adapted from LeBlanc K, Baranoski S. Skin tears: State of the science: Consensus statements for the prevention, prediction, assessment, and treatment of skin tears. *Adv Skin Wound Care*. 2011;24(9):2–15; and Reference 80: McNichol L, Lund C, Rosen T, Gray M. Medical adhesives and patient safety: state of the science. *J Wound Ostomy Continence Nurs*. 2013:40(4):362–376.

proliferation of malignant cells and infiltration of the skin, blood, and lymph vessels by tumors in patients with advanced cancer.[104] Unchecked local tumor extension inflicts widespread tissue damage and causes disfigurement, loss of vascularity with subsequent tissue hypoxia and necrosis, polymicrobial proliferation and fungating ulceration of the wound bed (see Figure 19.4).[104] MFWs are visible markers of underlying neoplastic disease,[105] predominately developing during the last 6 months of life,[106,107] and indicate a grave prognosis.

MFWs occur in patients with various types of cancer. Malignant wounds of the breast are most prevalent (63%), followed by head and neck (24%), then groin, genitals, and back (3%), with all other sites accounting for the remaining 8% (see Figures 19.5 and 19.6).[108]

MFWs afflict 5–14.5% of people with advanced cancer,[38,109,110] with more than half of those experiencing death within 24 weeks of discovery of the cutaneous lesion.[109] Average life expectancy ranges from 6 to 12 months.[110,111] Studies report grimmer survival rates for certain primaries from first appearance of cutaneous metastasis: 6 weeks for genitourinary cancers[112] and 3 months for lung, cervical, or esophageal cancers.[113] Additionally, one study reported a 30% reduction in average survival in patients

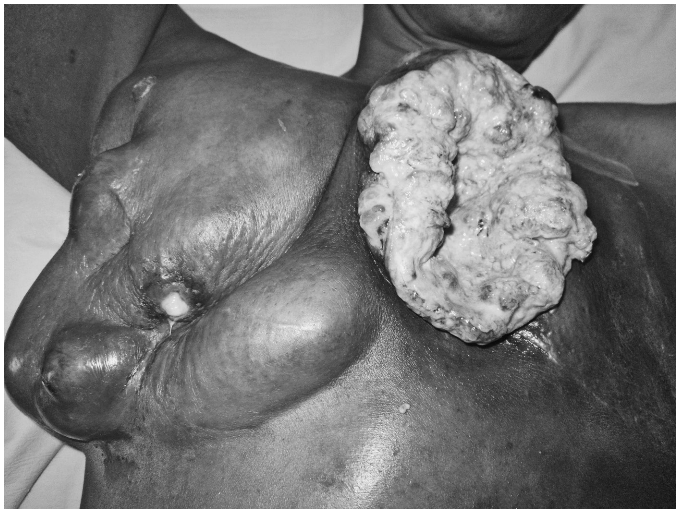


Figure 19.4 A 49-year-old African American woman with metastatic breast cancer and a malignant fungating wound of the breast.

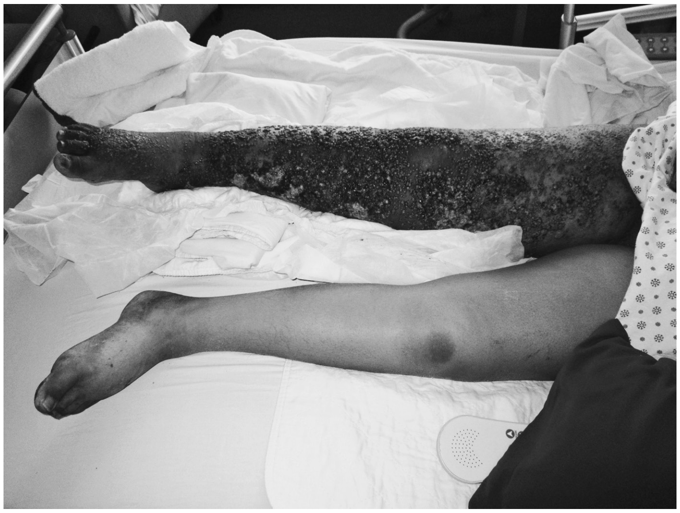


Figure 19.5 Malignant fungating wound of entire right leg with lymphedema from metastatic colon cancer.

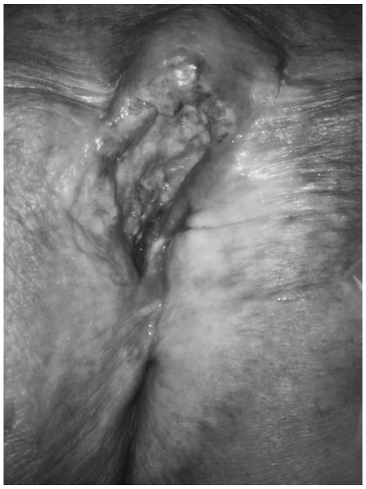


Figure 19.6 I. The first three steps to the PALCARE method: Prognosis, Advance care planning, and Living situation. P: 45-year-old Caucasian woman with metastatic vulvar cancer status post vulvectomy, radiation, and chemotherapy. She has a life expectancy of 2–3 weeks and a Palliative Performance Score of 30%. A: She has a do not resuscitate/do not intubate (DNR/DNI) order, declines hospitalization or heroic measures, and will accept oral and/or topical antibiotics. L: She is transferred to the hospice inpatient unit from home with uncontrolled pain, malodor, and excessive exudate from a vaginal malignant fungating wound. She was self-managing the wound with obstetric pads, showers, and frequent changes of underwear and pants when soiled. Her primary caregiver is overwhelmed and unable to care for her at home.
II. Course of hospice care. C: On admission to the inpatient unit (IPU), she screened positive for depression and anxiety, c/o painful moisture-associated skin damage (MASD) along the periwound/vaginal border, odor noted at the door of her room, and exudate that stained her underwear and pants two to three times per day. C/o intermittent abdominal pain, not controlled with four to five doses of short-acting opioid. A: Friable, yellow-pink tissue with moderate, yellow, foul exudate and circumferential periwound maceration and erythema. Odor noted at the door with dressing intact. R: Wound Care: Cleanse with warm soapy water via a peribottle, pat dry, 1% flagyl spray to wound bed, petrolatum-based barrier periwound and ABD pads held in place by Attends mesh undergarments. MASD resolved, odor and drainage were controlled within 3 days. Pain Management: Pain resolved with local care and a long-acting opioid and daily corticosteroids with a short-acting opioid for breakthrough pain. The short-acting opioid was administered a half hour before wound care and again after completion if needed. Psychosocial: Licensed clinical social worker and rabbi consulted for counseling; mirtazapine started for depression, insomnia and anorexia; and a short-acting benzodiazepine for anxiety as needed. E: IPU staff, patient, and her husband were educated in the wound care orders and protocol. The patient was able to participate in her own wound care but as her health and cognition failed, the staff assumed total responsibility until her death 2 weeks later.

with multiple sites of metastasis as compared to single-site cutaneous involvement.[114] Articles have also reported that malignant wounds disproportionately affect women and older adults.[108]As life-prolonging treatments continue to evolve and life-expectancy increases, it is reasonable to expect the percentage of people with MFWs to rise.

MFWs originate from one of three etiologies: primary skin neoplasms, local extension and integumentary erosion from primary tumors or malignancy recurrence, and from metastatic cutaneous lesions.[109,115,116] MFWs may arise from any type of underlying malignancy, but the most common involvement includes neoplasms of the breast, lungs, skin, and gastrointestinal tract.[111,114,116] Metastatic invasion of the basement membrane is essential for the development of an MFW. Characteristically, these wounds have a tendency to expand rapidly[111]; to occur along pathways of least resistance such as surgical incisions, tissue planes, and blood or lymph vessels[111]; and a tendency to cause lymphedema secondary to local lymphatic vessel invasion.[111]

Assessment

Initially, MFWs present as inflammation, peau d'orange appearance, smooth raised nodules varying in size and pigmentation, erythematous plaques or patches, areas of alopecia, or violaceous papules.[116] They rapidly progress to cauliflower-shaped lesions (proliferative) or an ulcerated area (erosive), sometimes forming fistulas or a sinus tract.[106,116–118] Carville differentiated fungating from ulcerating lesions by morphology, the former protruding and grotesque, the latter cavity-forming, with both prone to bleeding, infection, and malodorous exudate.[119] A survey of nurses reported a variety of MFW morphologies: ulcer (56%), fungating shape (31%), a crust (25%), nodular shape (24%), crater shape (23%), and other (6%).[38] Initial and periodic, detailed wound assessment is essential in monitoring the deterioration of MFWs for the development of new or worsening advanced symptoms.

MFWs have a negative impact on psychosocial, physical, and functional health[68,69,117,118] resulting in compromised QOL.[75] Given the high symptom burden experienced and the incurable nature of their wounds, this population will require aggressive palliative care until death. Developing a pragmatic, patient- and family-centered palliative wound care plan is essential to alleviate suffering. The case study of the 45-year-old woman with stage IV vulvar cancer and a vaginal MFW presented at the beginning of this section is used to demonstrate the use of the PALCARE mnemonic (see Box 19.2) as a framework for developing a holistic, systematic, patient-centered plan of care.

Psychosocial Aspects of Care

Individuals with MFWs may struggle with both advanced cancer-related and treatment-related symptoms and symptom clusters, as well as side effects from palliative therapies. Lawton, during her 10-month observational study of hospice patients enduring horrific physical and psychological suffering, introduced the concept of being "unbounded."[69] The state of becoming unbounded was caused by odors, exudate, pain, bleeding, and disfigurement as a result of "the disintegrating, decaying body," with the dying experiencing marginalization, isolation, and loss of self and social identity.[69] Her study notably included patients with fungating tumors of the head and neck, groin and genitalia, and breast. The presence of a malignant wound was found at times to cause more psychological suffering than the cancer diagnosis itself.[67]

Body image has a great impact on psychological well-being because it is associated with one's identity. Studies on femininity demonstrate a loss of confidence among women with MFWs. Because of the breast's connection with sexuality and being female, women report feeling less attractive and avoid intimacy with their partners.[120] Furthermore, women report feeling mutilated and disgusted by their wounds, as though they are witnessing their bodies decompose.[120] As a result, these individuals feel as though they have lost control over their lives and are marginalized, subsequently withdrawing from society.[60,120,121]

The hospice team uses timely screening, assessment, interventions, and referrals in addressing these psychosocial issues.

Box 19.8 Patient Health Questionnaire 2 (PHQ2)

1. Over the past 2 weeks, have you felt down, depressed, or hopeless?
2. Over the past 2 weeks, have you felt little interest or pleasure in doing things?

Source: Adapted from Reference 122: Pfizer. Patient Health Questionnaire screeners. http://www.phqscreeners.com (accessed October 23, 2017).

Depression and anxiety screening tools, such as the Patient Health Questionnaire 2[122] (see Box 19.8) and the Generalized Anxiety Disorder 7[122] (see Box 19.9), should be used to identify patients at risk for depression and anxiety and allow for timely interventions and referrals. The authors recommend screening on entry into the hospice program, at least every 2–4 weeks thereafter, and with each contact by the hospice nurse practitioner or hospice medical director. Decisions to refer to a licensed clinical social worker (LCSW) or psychologist for counseling or to a psychiatrist for evaluation and pharmacologic recommendations should be a shared decision with the patient and family.

Complementary Alternative Medicine

The role of complementary alternative medicine (CAM) in the holistic care of MFWs is promising, although research is limited. Massage and touch therapy, music therapy, aromatherapy, and occupational therapy have been shown to decrease suffering and improve overall well-being.[60] Research in the area of CAM ranges from expert opinion and case reports to small, nonrandomized qualitative studies. Guided imagery and meditation may also prove to be therapeutic, although no studies to date examine these techniques in patients with MFWs.

Spiritual Aspects of Care

Suffering and limited prognosis cause patients to consider their own mortality[62] and review their existential beliefs and connection to spirituality. Loss of hope may occur as the fungating wound grows in size, new lesions appear, or new symptoms emerge.[121,123] Additionally, five studies found MFWs were constant reminders of advanced and incurable disease, robbing patients of hope[60–62,65,67]: "this wound looks as if death is more and more near me. I can't escape."[61] Visibility of the tumor provoked fears that it mirrored what was occurring internally and conveyed a threat to their body and existence.

Box 19.9 Generalized Anxiety Disorder 7

Over the past 2 weeks, how often have you been bothered by the following problems?

1. Feeling nervous, anxious, or on edge
2. Not being able to stop or control worrying
3. Worrying too much about different things
4. Trouble relaxing
5. Being so restless that it's hard to sit still
6. Becoming easily annoyed or irritable
7. Feeling afraid as if something awful might happen

Source: Adapted from Reference 122: Pfizer. Patient Health Questionnaire screeners. http://www.phqscreeners.com (accessed October 23, 2017).

Additional Management Considerations in Malignant Fungating Wounds

Pain associated with MFWs has multiple etiologies, detrimental effects on QOL,[75] and is a common distressing complaint.[61,65,66,123–125] Pain in advanced cancer is one of the most common and distressing symptoms reported. Pain assessment must include wound- and non–wound-related pain or discomfort and exploration of temporary and persistent wound pain etiologies, and the use of a valid and reliable tool is recommended. The total pain approach (Box 19.4) includes symptom management for malignancy-related pain, interdisciplinary involvement to address psychosocial or spiritual factors, and specialist-level wound care for local discomfort.

Topical antimicrobial therapy and absorbent dressings, combined with cleansing and odor-eliminating interventions, have been the mainstay of MFW odor and exudate treatment. Despite multiple studies, a Cochrane Review[126] identified only one randomized control trial by Kalemikerakis[127] that provided weak evidence suggesting silver foam dressings may reduce malodor.[126] The effect of topical antimicrobial dressings on microbial resistance, biofilms, and the characterization of microbiomes in MFWs is also largely unknown. Table 19.5 lists select interventions that may be used to control odor and exudate.

Postsurgical bras (i.e., Dale bras), Lycra, and Attends undergarments to secure dressings, minimize bulk effect, normalize appearance, and reduce MARSIs are recommended. Carrying an extra set of clothing in the event of strike-through is also suggested.

Goals of care discussions surrounding bleeding are an integral part of advance care planning for the hospice patient with an MFW because interventions may range from the benign (i.e., direct pressure, vitamin K replacement, modification of topical antimicrobial therapy) to aggressive and/or invasive (i.e., vascular interventions for hemorrhage, blood products, radiation). The cause of bleeding in advanced cancer is usually multifactorial and may be thought of in terms of reversible and irreversible factors (see Box 19.10).

If MFWs are in close proximity to large vessels (i.e., femoral or carotid artery), the sensitive probing of patient wishes in the event of hemorrhage should be undertaken. This discussion should include comfort (sedation, pain management, temperature control, and family support) versus emergent transfer to a general inpatient level of care or acute care setting (i.e., emergency room).

Marjolin's Ulcers, Calcinosis Cutis, Calciphylaxis, and Radiation Dermatitis

Marjolin's ulcers, calcinosis cutis, calciphylaxis, and radiation dermatitis are wounds less commonly encountered in palliative settings. These wounds have the propensity to cause advanced symptoms and intense suffering, presenting unique challenges for the palliative care service or hospice team.

Marjolin's Ulcers

Like MFWs, Marjolin's ulcers have cancerous wound beds; however, their etiology is quite different. Marjolin's ulcers are rare, malignant degenerations that most commonly arise from areas

Box 19.10 Bleeding Etiologies in Advanced Cancer

Malignant fungating wounds

- Direct vessel invasion
- Microvascular bleeding
    - Dressing selection/removal
    - Friable tissue: bioburden

Thrombocytopenia

- Chemotherapy
- Paraneoplastic syndromes
- Idiopathic thrombocytopenia purpura
- Thrombotic thrombocytopenia
- Invasion of tumor cells in bone marrow

Cancers of the bone marrow

- Multiple myeloma, leukemia, lymphoma

Coagulopathy

- Liver disease
    - Primary liver cancer
    - Metastatic liver cancer
- Vitamin K deficiency

Disseminated intravascular coagulation

- Infection, malignancy, trauma
- High-dose chemotherapy
    - Cyclophosphamide
- Radiation (bone marrow production sites, such as ilia)
- Surgery
- Anticoagulation for deep venous thrombosis, pulmonary embolism, atrial fibrillation, stroke

Source: Adapted from Reference 128: Kurtin S. Alterations in hematologic and immune function. In: Itano JK, editor. *Core Curriculum for Oncology Nursing. 5th edition*. St Louis (MO): Elsevier Saunders; 2015:322–338; and Reference 133: Maloney KW. Metabolic emergencies. In: Itano JK, editor. *Core Curriculum for Oncology Nursing. 5th edition*. St Louis (MO): Elsevier Saunders; 2015:478–493.

of chronic inflammation or injury, developing over years or even decades (see Box 19.11).[130,131] One recent review found that the average time for malignant transformation is 29 years.[132] The ulcers were first described by French surgeon Jean Nicholas Marjolin in 1784, after observing villous changes arising in a burn scar.[133] Classically, these ulcers transform from their original etiology to a squamous cell carcinoma (SCC), but basal cell carcinomas and malignant melanoma have also been reported.[131] Marjolin's ulcers may arise in nearly any location on the body, but they are most commonly found in the lower extremities.[132] They are associated with a poor prognosis.[133]

Marjolin's ulcers are diagnosed by attaining both a thorough history and physical (including a detailed wound assessment), and a tissue biopsy. The magnitude of the wound, clinical presentation, and the patient's goals of care will guide more extensive oncologic workups. These ulcers may not present as a classic SSC, but as a characteristic triad of nodule formation, induration, and ulceration suggestive of the diagnosis.[133] Other clinical signs may include chronic ulceration greater than 3 months, rolled wound margins, an irregular base or margins, excessive granulation tissue, crusting over, and an increase in size despite appropriate treatment.[132,133] Marjolin's ulcers may also be associated with advanced symptoms: bleeding on contact, foul odor, purulent exudate, pain, pruritus, and bulk effect.[131]

Box 19.11 Skin Pathologies Giving Rise to Marjolin's Ulcers

- Burn scars
- Traumatic wounds
- Venous ulcers
- Pressure injuries
- Osteomyelitis
- Frostbitten tissue
- Snakebites
- Leprosy ulcers
- Lupus rashes
- Urinary fistulas
- Irradiated skin
- Vaccination sites
- Skin graft donor sites
- Discoid lupus erythematous
- Pilonidal abscess
- Hidradenitis suppurativa

Source: Adapted from Reference 132: Bowers RF, Young JM. Carcinoma arising in scars, osteomyelitis, and fistulae. *Arch Surg*. 1957;80:564–570; and Pekarek B, Buck S, Osher L. A comprehensive review on Marjolin's ulcers: Diagnosis and treatment. *J Am Coll Clin Wound Spec*. 2011;3(3):57–61.

Treatment

Early detection with immediate referral to plastic surgery for biopsy and wide excision with grafting are the key to successful curative treatment.[131] Palliative care practitioners are likely to encounter Marjolin's ulcers that have either progressed beyond curative treatment or are considered secondary to a more dire diagnosis. Palliative treatment of Marjolin's ulcers follows the same guiding principles of palliative wound care previously discussed in this chapter.

Calcinosis Cutis and Calciphylaxis

The exact etiology behind calcinosis cutis and calciphylaxis is unknown, but abnormal fluctuation in calcium levels and tissue damage is common to both. Calcinosis cutis is characterized by abnormal deposition of insoluble calcium salts in the skin.[134] The cause may be idiopathic (with normal calcium levels) or due to an underlying disease process that causes hypercalcemia, such as metastatic cancer, chronic kidney disease, hyperparathyroidism, or sarcoidosis.[134] The wounds are commonly found on the lower extremities but can be located anywhere. Calciphylaxis is a closely related disorder characterized by calcification of small vessels of the skin and subcutaneous tissues resulting in localized ischemia and tissue damage.[135] Two clinical forms exist, differing in location of the lesions and prognosis. Proximal lesions on the trunk or thigh carry a worse prognosis than distal lesions.[135] Calciphylaxis may affect multiple body areas including the fingers and toes and occasionally even the peristomal skin.[136] Calciphylaxis is usually associated with end-stage renal disease, with or without hemodialysis.

There are no specific laboratory tests to diagnosis either skin pathology. However, serum calcium and phosphate levels, a comprehensive metabolic panel, and a serum parathyroid hormone level should be considered regardless of underlying etiology.[137] Additional laboratory studies, imaging, and tissue biopsy may be indicated.[137]

Treatment

Treatment is complex and should be based on goals of care. If possible, the underlying disease process should be managed, electrolyte abnormalities corrected, and a plan for local wound care developed. There are no standard wound care protocols. Bryant and Nix recommend six general principles: (1) remove impediments from the wound (loose, hard, calcium deposits and slough), (2) balance wound bed moisture, (3) reduce bioburden (prevent and treat infections), (4) reduce edema, (5) control venous insufficiency, and (6) protect periwound skin.[137] One case study of peristomal calciphylaxis reported successful use of a methylene blue + gentian violet foam ring in the peristomal area, a secondary hydrocellular adhesive foam dressing to provide a surface for the pouching system to adhere to, and barrier strips to enhance the pouching system seal.[136] A 24-hour wear time was eventually achieved.

Radiation Dermatitis

Ninety-five percent of cancer patients receiving radiation therapy will develop some form of radiation dermatitis which may result in treatment delay, disfigurement, pain, and/or diminished QOL.[138,139] Radiation dermatitis is also known as *radiodermatitis, radiation burn, radiation injury*, or *radiation-induced skin reaction*.[139] Radiation injures rapidly dividing cells of the epidermis (stratum germinativum, stratum spinosum) and epidermal appendages: hair follicles, sebaceous glands, and nails.[138,140] This results in impaired strength and elasticity of the integumentary, immune compromise, vulnerability to chemical and mechanical trauma, and delayed healing.[138,140]

Radiation dermatitis may be acute or delayed. Early or acute side effects of ionizing radiation delivered to the skin during cancer treatment may manifest as erythema, dry desquamation (see Figure 19.7), or moist desquamation (see Figure 19.8).[139] The acute reactions result from a combination of direct radiation injury and subsequent inflammation.[143] Concurrent chemotherapy or targeted therapy increases the risk of skin toxicity,[138] as do larger number of doses and higher total doses of radiation due to cumulative effects.[137] Delayed or chronic reactions may occur months or even years after the completion of radiation therapy and usually develop as chronic dermatitis and/or skin fibrosis.[139,140]

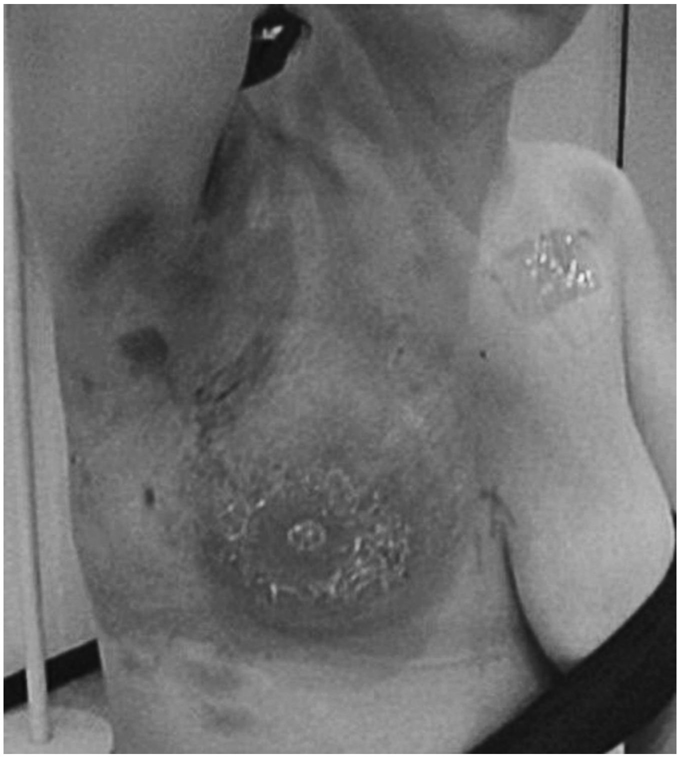


Figure 19.7 Dry desquamation and moderate erythema in a breast cancer patient undergoing radiation treatment.

Assessment and Grading

Skin assessment should be performed prior to the start of radiation and regularly thereafter. Universally, all patients should be assessed for erythema, edema, skin breakdown, pain, skin sensitivity, and tightness. Those with dry desquamation should additionally be assessed for xerosis, pruritus, and scaling.[138,139] The skin of patients with wet desquamation should be inspected for moistness, tenderness, crusting, and the presence of serous exudate and superimposed infections.[139] Several severity grading scales for radiation dermatitis exist, but the National Cancer Institute (NCI) Common Toxicity Criteria for Adverse Events (CTCAE) is the most commonly used in the United States.[138] The CTCAE defines acute reactions as those occurring within 86 days after therapy.[138] Table 19.11 displays the definition and prominent characteristics of each grade of the CTCAE scale.[141]

Treatment

Broadly, goals of treatment should include the promotion of healing, prevention of infection, and the management of advanced symptoms (pain, pruritus, exudate). There is a dearth of evidence supporting specific recommendations in the treatment of acute and chronic radiation dermatitis.[139] General skin care during radiation therapy includes the use of mild soaps and deodorants, loose-fitted clothing over the irradiated site, avoiding sun exposure and scratching, and adequate nutrition.[138,139] Prophylactic use of steroids and silver sulfadiazine (SSD) has shown promise in the reduction of acute radiation dermatitis.[139] Calendula and SSD have weak evidence supporting their effectiveness in acute reactions.[138] One case study of a 57-year-old man with neck radiation burns reported the effectiveness of slow-released, silver hydrofiber dressings in improved healing and decreased dressing

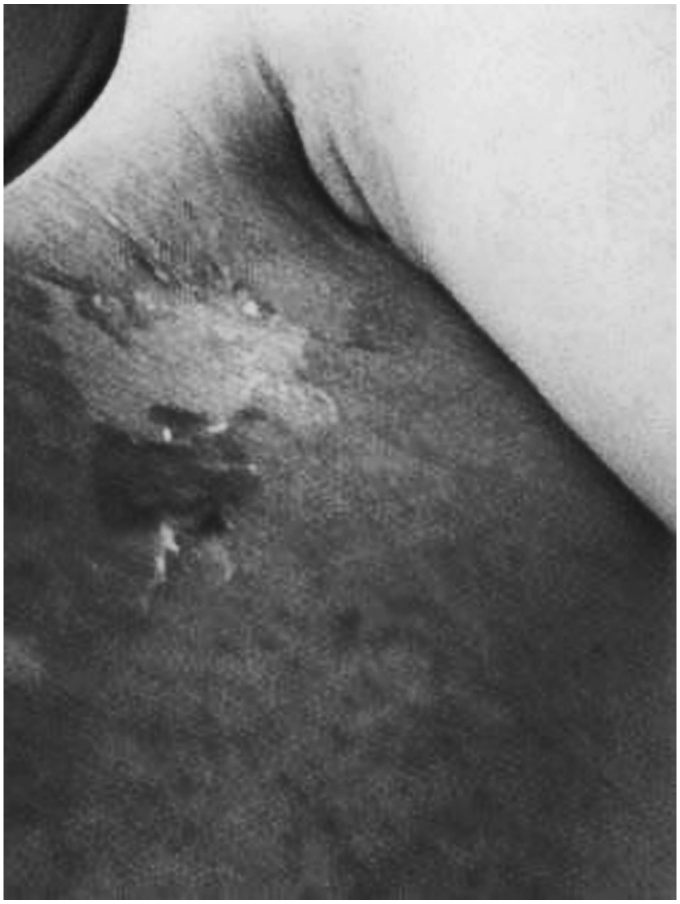


Figure 19.8 Moist desquamation and severe erythema in a breast cancer patient undergoing radiation treatment.

changes and pain.[142] Another case study described complete healing of wet desquamation in a 51-year-old woman with breast cancer after mastectomy, chemotherapy, and radiation using trypsin, Balsam Peru, and hydrogenated castor oil ointment.[143]

Table 19.11 Common toxicity criteria for adverse events scale: radiation dermatitis

Grade of reaction	Definition and characteristics
Grade 1	Faint erythema or dry desquamation. Arising within the first 2-4 weeks of treatment, these reactions cause skin redness and warmth and a rash-like appearance. The patient may complain the skin feels tight or sensitive.
Grade 2	Moderate to brisk erythema; patchy, moist desquamation usually confined to the skinfolds or creases. Moderate edema, dryness, pruritus, and flaking of skin layers (dry desquamation) also may occur.
Grade 3	Moist desquamation in areas other than creases and skinfolds. Bleeding may arise from minor trauma, such as abrasion.
Grade 4	Life-threatening consequences, such as full-thickness skin ulcers, necrosis, and spontaneous bleeding.
Grade 5	Death

Source: Adapted Reference 141: from Chen AP, Setser A, Anadkat MJ et al. Grading dermatologic adverse events of cancer treatments: the Common Toxicity Criteria for Adverse Events Version 4.0. *J Am Acad Dermatol*. 2012;64(5):1025–1039.

Pentoxifylline for the reduction of fibrosis has been used with success in patients with chronic radiation-induced telangiectasia and fibrosis.[144]

Palliative Care of Continent Diversions, Incontinent Diversions, and Fistulas

Palliative care of the patient with a urinary or fecal diversion or fistula centers on expert guidance to manage advanced symptoms and adapt product selection and utilization to the progressive cognitive, psychomotor, and physiologic decline experienced in advanced or terminal illness, with an eventual shift of responsibilities to the caregiver.

Case Study: A Patient with Metastatic Colon Cancer

A 55-year-old man with widely metastatic colon cancer and a malignant bowel obstruction and moderate-output abdominal fistula was admitted to an inpatient hospice unit for end-of-life care after his wife and daughter decided they were no longer able to care for him at home. Due to the change in his abdominal planes from abdominal distention and the large amount of effluent (467 mL per day), the fistula pouching system leaked, causing perifistula moisture-associated skin damage. The erosions and inflammation were very painful, and pouch changes distressed both the patient and family. They called the hospice team and the decision was made to transfer him to the inpatient unit (IPU).

Continent and Incontinent Fecal and Urinary Diversions

No published research specifically addresses the current prevalence, management, or quality-of-life aspects related to ostomy issues in men, women, and children facing life-limiting illness.[9] An ostomy is a surgically created stoma for the elimination of urine or stool that can be permanent or temporary.[145] Indications for stoma creation are listed in Box 19.12, and Table 19.12 describes the different continent and incontinent fecal and urinary diversions

Box 19.12 Indications for Stoma Creation

Malignancy

- Colon, rectal, or anal cancer
- Bladder cancer

Nonmaligancy

- Inflammatory bowel disease (IBS): Ulcerative colitis, Crohn's disease
- Trauma
- Congenital disorders: Hirschsprung's disease, imperforate anus
- Diverticular disease
- Severe neurogenic bladder not otherwise manageable

Source: Adapted from Wound Ostomy and Continence Nursing Society. WOCN Society clinical guideline: Management of the adult patient with a fecal or urinary ostomy—an executive summary. *J Wound Ostomy Continence Nurs*. 2018;45(1):47–55.

Table 19.12 Continent and incontinent fecal and urinary diversions

Type of diversion	Continent or incontinent	Description
Ileostomy	Incontinent (fecal)	A stoma (surgical opening) constructed by bringing the end or loop of ileum out onto the surface of the skin. A one or two-piece pouching system is then worn to collect the effluent.[146]
Colostomy	Incontinent (fecal)	A stoma (surgical opening) constructed by drawing the healthy end of the large intestine or colon through an incision in the anterior abdominal wall and suturing it into place. A one or two-piece pouching system is then worn to collect the effluent. Conversely, colostomy irrigation and a stoma cap may be chosen for patients with distal stomas.[146]
Continent ileostomy (Koch pouch)	Continent (fecal)	The small intestine is connected to an internal, S-shaped reservoir created from a section of ileum. A one-way valve is constructed through which a Medena catheter (30 Fr) is inserted 4–8 times a day to drain the fecal effluent.[146]
Urostomy (ileal conduit)	Incontinent (urinary)	The ureters are surgically resected from the bladder and drain the urine into a detached section of ileum. The end of the ileum is brought out through a stoma in the abdominal wall. The residual small bowel is reanastomosed with the residual terminal ileum. A collection pouch fitted with a belt is then worn snugly against the abdomen and over the stoma to collect the urine.[147]
Ureterostomy	Incontinent (urinary)	One or both ureters are detached from the bladder and brought through the abdominal wall to form a stoma. A collection pouch fitted with a belt is then worn snugly against the abdomen and over the "ureteral buds" or stomas to collect the urine as it passes through the ureters.[147]
Heterotopic continent bladder replacement (Indiana pouch)	Continent (urinary)	Following cystectomy, an ileal or ilio-cecal segment is used to form a reservoir. The ureters are connected to the reservoir. A one-way valve is constructed through which a catheter is inserted 4–6 times a day and at bedtime to drain the urine.[147]
Orthotopic bladder substitution (neobladder)	Continent (urinary)	Treatment of choice when the intent is curative. This is closest to the natural bladder's urine storage and voiding function. Following cystectomy, a reservoir is created from a section of ileum and situated in the pelvis minor and connected to the patient's urethra. Continence is achieved through the patient's own sphincter.[147]

the palliative care nurse may encounter. Most stomas require a pouching system which maintains peristomal skin health, provides a secure seal, and allows the patient with an ostomy to maintain their functional performance status. Pouching change procedures for either one- or two-piece pouching systems can be complex and challenging and include essential tasks such as emptying and removing the pouching system, washing and drying the skin, measuring the stoma, putting on a new pouching system, and disposing of the used pouching system.[9] As taxing as this process can be for an otherwise "well" person with a stoma, basic ostomy care, supply ordering, pouch disposal, and trouble-shooting leakage may present an insurmountable challenge for persons with a life-limiting illness. Specifically, palliative care ostomy challenges may include the presence of motor, sensory, vision, and cognitive deficits as the illness progresses, as well as peristomal complications and pharmacological considerations.[9]

Motor and Sensory Deficits

An overview of the chronic and often lethal diseases the nurse will commonly encounter in palliative care and hospice, as well as their potential effect on the person with a stoma, must begin by reiterating the importance of obtaining a complete patient history and performing a physical assessment. It is essential to obtain a meticulous individualized evaluation of the patient's history of the present illness, past or current medical or surgical treatments, allergies (including to latex or adhesives), medications (including herbal, over-the-counter, and homeopathic remedies), and functional performance level.[9] A psychosocial evaluation and an ostomy and/or continence assessment also must be performed.

For many persons living with chronic, debilitating illness or life-limiting disease, alterations in their physiological functioning and the often devastating sequelae of their treatment regimens may lead to motor and sensory deficits. Neuromuscular illness can affect people with stomas in numerous debilitating and often painful ways (see Table 19.13).[148–153]

Progressive neurodegeneration, peripheral neuropathies (from either disease process or treatment modality), and autoimmune diseases may interfere with a person's ability to care for his or her stoma, requiring the expertise of the WOC nurse to help modify the pouching system or care routine or teach the caregiver how to care for the stoma, if accommodation is not possible. Key to ensuring adherence to the treatment plan and stoma health, as well as to maintaining the patient's autonomy and self-esteem, is the development of a realistic plan of care for the palliative care or hospice patient.[9]

For patients with impaired motor skills secondary to disease or treatments (see Table 19.13), it is important to realistically assess patient functional status, enlist the help of a caregiver or staff members if the patient is institutionalized, and recommend options that simplify ostomy care. Velcro pouches that eliminate the need to use clips, one-piece appliances, and two-piece pouches that can be attached to a skin barrier with one hand for easy applications may be suggested. Convatec's (Skillman, NJ) moldable technology also may be an option for persons with minimal manual dexterity, vision impairment, chronic metacarpal joint pain, or polyneuropathies of the hands. These skin barrier products do not need to be cut (eliminating the need to manage scissors or visualize patterns), and they are molded to fit snugly against the stoma, facilitating adaptation to changing stoma size and shape.[9] Colostomy patients may consider using a disposable, closed-end pouch, thus eliminating the need for a clip, while urostomy patients may need to try various spouts and tabs to find the product easiest for them to use.[154] The WOC nurse may need to refer a patient to occupational therapy to assist in teaching manual skills and to recommend needed adaptive

Table 19.13 Advanced neuromuscular disease and stoma care considerations

Illness/treatment modality	Pathophysiology	Sequelae	General and stoma-specific considerations
Advanced Parkinson's disease	Loss of dopaminergic neurons and the appearance of Lewey bodies[166]	Freezing, hypokinesis, akinesis, dyskinesias, and dystonia[148]	Careful assessment to ensure maximization of dopaminergic agents. May necessitate collaboration with the prescribing neurologist.
Multiple sclerosis (MS)	Multifocal plaques of demyelination within the central nervous system.[148] If diagnosed under the age of 40 years, recurring episodes of neurologic impairment followed by periods of spontaneous remission are common.	Spasticity[148] Pain syndromes have been reported in up to 76% of patients.[148]Along with pain syndromes, dysesthesias are extremely common.	Spasticity is usually treated with baclofen or tizanidine. May respond to both pharmacologic and nonpharmacologic interventions. Consider caregiver training early in the disease process because recurring episodes may be sporadic and debilitating or increase in frequency with increasing age
Amyotrophic lateral sclerosis (ALS)	Loss of both upper motor neurons (UMN) in the motor cortex and lower motor neurons (LMN) in the brainstem and spinal cord[148]	Spasticity, slow movements, hyperreflexia, and poor dexterity are sequelae of UMN disease. Weakness, atrophy, reduced tone, and hyporeflexia are due to LMN involvement[148]	5,000 new cases of this irreversible disease diagnosed each year, with an average lifespan post diagnosis of 3–5 years.[148] Persons with ALS and a stoma will need caregiver assistance, whether at home or in a long-term care setting, at some point in their life spans.
Stroke	May affect sensory or motor function and often both depending on location and extent of injury. May be ischemic (thrombotic, embolic), hemorrhagic (intracerebral, subarachnoid), or lacunar.	Hemiparesis Ataxia Paresthesia Adhesive Capsulitis (Frozen shoulder)	Presents the challenge of caring for a stoma with one, possibly the nondominant, hand. Challenges utilizing or accessing toilet facilities. Inability to feel a clip or flange, or to recognize it as such (stereognosis).
Quadriplegia or paraplegia	Spinal cord trauma, spinal stenosis, or cord compression due to primary tumor or metastasis	Injuries from C4 through C7 may effect shoulder and arm musculature; C6 through C8 (forearm extensors and flexors); and C8 through T1 (hand musculature).[149] Total cord transection syndrome results in the loss of all types of sensation and motor function below the level of the lesion.[149]	May lack the physical coordination to perform majority of gross and/or fine motor skills needed to perform daily care, depending on level of injury. Focus on modifying a plan to accommodate abilities or teach caregiver ostomy care.
Peripheral neuropathy	Common diseases causing polyneuropathies include diabetes, alcoholism, shingles, HIV/AIDS, hepatitis C, rheumatoid arthritis (RA), end-stage kidney or liver disease, and tumor invasion, as in brachial plexopathy commonly seen in metastatic lung cancer.[150] Chemotherapy-induced peripheral neuropathy (CIPN) is a well-known side effect of cancer treatment.[151]	Symptoms may range in severity from minimal, transient numbness and tingling in the extremities to burning pain and lack of coordination.[149]	Most notorious classes of chemotherapeutic agents responsible for CIPN are the taxanes (paclitaxel, docetaxel, Abraxane), vinca alkaloids (vincristine, vinblastine, vinorelbine), and platinum compounds (cisplatin, carboplatin, oxaliplatin).[151] Oxaliplatin, in combination with 5-FU and leucovorin, is considered first-, second- or third-line therapy for metastatic colon and rectal cancer; the recipient commonly has either a temporary or permanent ostomy.[151]
Rheumatoid arthritis (RA)	Acute and chronic inflammation in the synovium associated with joint tissue destruction.[153] Joint damage that results in disability often occurs early in disease (<2 years). Although the course of RA varies and patients may have long clinical remissions or intermittent disease, the majority of patients have progressive disease that can lead to joint destruction and instability.[153]	Loss of joint mobility and dexterity, as well as crippling pain, accompany RA.[153]	Must be diligent about pain control during acute flares or with end-stage disease. The loss of hand dexterity could impair the patient's ability to apply and remove a clip, cut a pattern, or empty a pouch.

Source: Reprinted with permission from Reference 9: Tilley C. Caring for the patient with a fecal or urinary diversion in palliative and hospice settings: A literature review. *Ostomy Wound Manage.* 2012;55(1):24–34.

devices. A thorough assessment also may show that self-care is not possible. In this instance, caregiver possibilities must be explored for providing daily stoma care or, in the case of a continent diversion or neobladder, regularly scheduled intubation. If this resource does not exist or is not available, home care agencies or long-term care placement may be necessary.[9]

Vision Deficits

Vision deficits are common among palliative patients and are an often-overlooked complication of chronic illnesses. In ostomy care, compromised eyesight can greatly hinder the ability of the patient with a stoma to measure for an appliance, note peristomal complications, or empty the pouch. Ultimately, the potential inability to perform self-care may encroach on the patient's independence, which can negatively influence body image.[145] Diabetic retinopathy,[159] conjunctival erythema (the "red eyes of uremia")[156] in patients with chronic kidney disease (CKD),[156] primary brain tumors,[157,158] and MFWs of the head and neck can be devastating to physical structures of the eye and vison.[10] The palliative care nurse may also encounter secondary ocular manifestations of rheumatoid arthritis[163] and visual dysfunction secondary to multiple sclerosis (MS). Surgery, such as enucleation or local resection and brachytherapy or external beam radiation, are also possible causes of blindness.[157,158] Although relatively uncommon, certain chemotherapy agents acting as either single agents or in combination therapies are known to induce ocular toxicities (see Table 19.14).[160]

There are multiple strategies that may be used to address visual deficits in patients with stomas. Educational materials with large font on blue- or cream-colored paper that reduces glare is suggested.[161] Bright lights, readers, and magnifying glasses also may be needed. Audiotapes with step-by-step instructions that can be conveniently played as frequently as the patient with a stoma or caregiver require may be employed.[162] In the absence of peripheral neuropathy, focus on the patient's strength and keen sense of touch.[163] Changing the ostomy appliance when the stoma is not functioning (i.e., when there is no output) and utilizing a two-piece pouching system are recommended, because it is easier to center the skin barrier by feeling the stoma by touch.[163] If the patient has an ileal conduit, he or she may be taught to wick the urine with a tampon or dental wick, both to keep the peristomal skin dry and to help center the skin barrier.[9] Tactile aides also have been developed by Coloplast Corporation (Marietta, GA).

Table 19.14 Chemotherapy and resultant ocular toxicities

Ocular toxicity	Chemotherapeutic agent
Epiphora	Cyclophosphamide, methotrexate, and 5-fluorouracil
Retinopathy	Cisplatin, etoposide, tamoxifen, interferon
Corneal or conjunctival damage	Carmustine, mitomycin
Glaucoma	Interferon
Cataracts	Tamoxifen, busulphan, methotrexate
Optic nerve or oculomotor nerve damage	Carmustine, vinblastine, vincristine
Optic neuritis	Cisplatin, tamoxifen

Source: Printed with permission from Reference 9: Tilley C. Caring for the patient with a fecal or urinary diversion in palliative and hospice settings: A literature review. *Ostomy Wound Manage.* 2012;55(1):24–34.

Cognitive Deficits

The successive stages of the cognitive learning process include the acquisition of knowledge, comprehension, application (the patient can apply the knowledge to ostomy care), synthesis, and evaluation (the patient performs ostomy care independently and recognizes when to ask for help).[154] The adult learner must be evaluated for the ability to achieve each component of the learning process with the goal of developing a realistic plan of care.

Many disease processes may cause cognitive deficits in the palliative care population.[148,164,165] The ostomy patient diagnosed with one of these diseases will eventually experience loss of memory and cognitive skills, as well as functional impairment. The WOC and palliative care nurse will need to be vigilant about decline in any of these areas because of their impact on daily ostomy care and the eventual added caregiver burden in the later stages of the disease.[9] Ongoing assessment of cognitive function is critical; interventions by the WOC nurse must be directed at the patient's level of functioning. Early in the cognitive disease trajectory, it is prudent for the palliative care nurse to identify one or more caregivers willing to learn about and assist with the patient's ostomy care. At early stages of memory loss, the patient may need visual reminders to prompt him or her to empty the pouch, intubate a continent diversion, or order equipment.[9] As memory and cognition diminish, step-by-step instructions, coaching/prompting, or visual aids may be considered.[9] Simpler pouches, such as pre-cut, one-piece appliances with Velcro closures, may be suggested. Eventually, the caregiver(s) will need to assume total daily care. This will necessitate the development of a teaching plan for either family or staff depending on home care or facility placement. The additional caregiver burden of providing stoma care or diversion intubation should be considered, and the need for respite care, support groups, or counseling routinely assessed.

Peristomal Complications

No statistical data or research directly describe peristomal complication prevalence and incidence in hospice and palliative care settings. Tilley has observed that these issues may be more pronounced or prevalent in the hospice population due to an increase in the frequency and duration of risk factors.[9] The Peristomal Skin Assessment Guide is a tool developed by the WOCN Society that provides basic guidance to clinicians on identifying and treating peristomal skin complications, including instructions for patient care and conditions that warrant referral to a WOC nurse.[166] Changes in abdominal planes, mucocutaneous separation, peristomal varices (caput medusa), and peristomal moisture-associated skin damage are among the most commonly encountered complications and will be discussed next.

Changes in Abdominal Planes

The peristomal plane is the surface area under the solid skin barrier and adhesive of the pouching system, extending out approximately 4 inches by 4 inches from the base of the stoma.[167] Assessing the plane with the patient lying down, sitting, and standing helps the practitioner decide on the type of skin barrier needed.[168] The following factors should be considered when selecting a pouching system: type of ostomy, stoma type and location, abdominal contours, lifestyle, personal preferences, visual acuity, and manual dexterity.[145,167,168] The skin surrounding the stoma should be assessed for firmness, excessive softness, unevenness caused by subcutaneous tumors, the presence of fungating wounds, and rounded protrusion caused by ascites, scars from prior surgeries, or areas of breakdown or trauma.[9] The type of pouching system included in the plan of care may need to be changed multiple times during the palliative to hospice continuum as the disease process progresses and abdominal tumor burden or ascites increase, weight loss occurs, or malignant bowel obstruction develops.[9]

The skin barrier should mirror the topography of the peristomal plane. In the case of a protruding abdomen or a peristomal plane with creases, wrinkles (as seen with excessive weight loss common to palliative care patients), or scars, a convex pouching system may be considered.[166] This system also may be used in patients with uneven planes due to tumors; barrier paste can be used to fill in uneven areas.[9] An extended-wear barrier, left in place for up to 7 days, may be chosen for a patient with a large abdominal tumor burden who is experiencing pain to decrease frequent changes and discomfort.[9] Premedicating with a short-acting opioid before the wafer change should be included in the plan of care, if indicated.[9] In all cases, the back of the skin barrier should be examined during each pouch change to ascertain undermining by effluent, and the skin should be assessed for irritant dermatitis.[145]

Mucocutaneous Separation

Mucocutaneous separation is the complete or partial detachment of the stoma from the surrounding skin (see Figure 19.9).[167] Risk factors include smoking, administration of corticosteroids, chemotherapy, abdominal radiation, diabetes, IBD, infection, malnutrition, or stoma necrosis,[167] and recurrence of malignancy or any of the chronic, debilitating diseases mentioned throughout this chapter.[9]

Corticosteroids, a mainstay in the treatment of pain, dyspnea, and cerebral edema, are used routinely in palliative care settings. The sequelae of diabetes and smoking, coronary artery disease, stroke, and end-stage renal disease are all common comorbidities seen in persons with chronic disease. Malnutrition and anorexia cachexia syndromes may be seen in several chronic, debilitating illnesses such as acquired immune deficiency syndrome (AIDS), chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), dementia, tuberculosis, malaria, CKD, liver disease, and rheumatoid arthritis.[169] Cachexia occurs in up to 70% of patients with advanced cancer.[169] Infection and recurrence of disease due to the debilitating nature of chronic illness may be anticipated.

Conservative management is key because, at end of life, the etiology of the complication most likely will not be correctable.[9] The wound left by the skin separation should be flushed with normal saline or tap water and filled with an absorbent material such as skin barrier powder, skin barrier paste, hydrofiber, or calcium alginates to absorb drainage as well as to prevent excessive soiling from urine or feces.[167] The pouching system is then placed over the area to protect from effluent. Consider using a two-piece system with a floating flange to facilitate comfort during pouch removal and reapplication.[167] A convex pouching system should be avoided because it may cause deeper tissue destruction and impaired healing at the stoma–skin junction.[167]

Peristomal Varices (Caput Medusa)

Peristomal varices occurring at the site of the stoma may be seen in patients with portal hypertension and end-stage liver disease (ESLD) either from malignancy or cirrhosis. This condition, often referred to as *caput medusae*, accounts for between 1% and 5% of all variceal bleeding.[170] A purple hue caused by dilation of mucocutaneous vessels and profuse bleeding may surround the stoma if it is eroded or traumatized (see Figure 19.10). In the case of acute bleeding, apply direct pressure, and if needed, cauterize with silver nitrate, use epi-soaked gauze or gel foam, or suture ligation.[9,167] Educate the caregiver about the need to (1) use skin barriers that are easily removable, (2) use adhesive removers when possible, (3) use flexible pouching devices, and (4) avoid rigid ostomy products and covexity.[167] If unable to stop the bleeding, instruct the caregiver to seek emergency care (if consistent with the patient's advance directives).

Peristomal Moisture-Associated Dermatitis

Peristomal moisture-associated dermatitis is defined as inflammation and erosion of skin related to moisture that begins at the

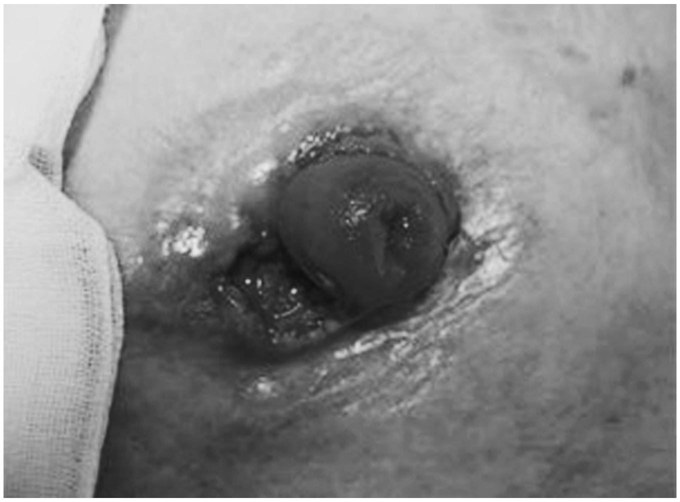


Figure 19.9 Partial mucocutaneous separation.

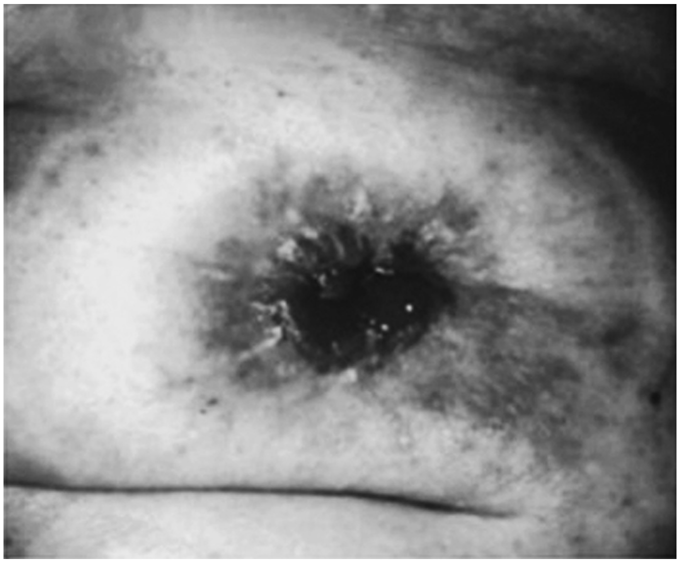


Figure 19.10 Peristomal varices.

stoma–skin junction and extends outward.[54] The etiology of peristomal moisture-associated dermatitis is prolonged exposure of the peristomal skin to urine or stool, perspiration, an external water source (swimming or bathing), or wound or fistula drainage.[54] The etiology of the skin damage drives the treatment plan and pouching system selection. The ultimate goal is to choose a pouching system that fits closely around the stoma and prevents leakage under the barrier.[167] Damaged skin can exude serous fluid and contribute to pouch adherence failure. "Crusting" is a technique that layers no-sting barrier film and stoma powder, forming a dry, protective barrier over denuded skin. The patient with a urostomy should connect the pouch to a bedside drainage bag at night to prevent urine from undermining the skin barrier.[167]

Fistulas

Fistulas negatively impact patients' QOL and present a unique challenge to the palliative care practitioner. A fistula is an abnormal passage or opening between two or more body organs or spaces. Fistulas are named either for the two communicating biological structures or spaces involved or the originating organ (see Table 19.15).[174] The majority of fistulas arise mainly from the gastrointestinal and genitourinary systems. The etiology of fistula development may be related to postoperative complications or spontaneous events. Surgical adhesions, a foreign body next to the suture line, tension on a suture line, breakdown of intestinal anastomosis, and compromised vascular supply can lead to fistula formation in the surgical patient.[175] Spontaneous occurrences may be seen in malignancy (malignant bowel obstruction, tumor invasion), small bowel obstruction, and Crohn's disease, while factors such as infection, poor nutritional status, steroid therapy, and endocrine and metabolic disorders can predispose patients with advanced and terminal illness to fistula development.[175] Fistulas occur in 1% of patients with advanced cancer.[176,177] Patients with gastrointestinal malignancies and those who have received pelvic irradiation are at highest risk.[175,176]

Table 19.15 Fistula terminology

Name	From	To
Enteroatmospheric	Intestine	Open wound base
Enterocolonic	Intestine	Colon
Enterocutaneous	Intestine	Skin
Enterovesical	Intestine	Bladder
Enterovaginal	Intestine	Vagina
Colocutaneous	Colon	Skin
Colovesical	Colon	Bladder
Pancreatic	Pancreas	Skin
Rectovaginal	Rectum	Vagina
Spit fistula (esophagostomy)	Esophagus	Skin
Vesicocutaneous	Bladder	Skin
Vesicovaginal	Bladder	Vagina

Source: Adapted from Reference 175: Toth PE, Hocevar BJ, Landis-Erdman J. Fistula management. In: Colwell JC, Goldberg MT, Carmel JE, eds. *Fecal and Urinary Diversions: Management Principles*. St. Louis: Mosby, 2004:33–59.

Box 19.13 ABC'S of Persistent Fistulae

A—Abscess, infection
B—Irritable bowel disease (IBD)
C—Cancer, Crohn's
D—Distal Obstruction
E—Epithelialization of tract
F—Foreign body
G—Gamma (XRT)

Source: Adapted from Reference 176: Shecter WP, Hirshberg A, Chang DS, Harris HW, Napolitano LM, Wexner SD, Dudrick SJ. Enteric fistulas: Principles of management. *J Am Coll Surg*. 2009;4:451–458.

Fistulas can be classified in different ways, but the most useful for the palliative care practitioner is by output. Low-output fistulas produce less than 200 cc/day of effluent (most will close spontaneously if they can epithelialize), moderate-output fistulas produce 200-467 cc/day (variable spontaneous closure rates), and high-output fistula produce greater than 467 cc/day (requires surgical therapy to close).[178] The goals of care may be palliative if spontaneous closure of the fistula, which usually occurs within 4–7 weeks, cannot be achieved. Factors that inhibit fistula closure include complete disruption of bowel continuity, distal obstruction, foreign body in the fistula tract, epithelialization of the tract, presence of cancer, previous radiation, and Crohn's disease (see Box 19.13).[175,176,178]

Mortality in patients with fistulas is related to fluid and electrolyte imbalances, malnutrition, failed operative closure, cholestatic liver failure, and sepsis.[182] Mortality may be as high as 10–30% in patients with enterocutaneous fistulas.[178,179] Box 19.14 lists frequent complications, some of them life-threatening, associated with fistulas.[178,179]

Diagnosis and Assessment

Fistulogram, a radiographic imaging technique where water soluble contrast is injected directly into the fistula tract to determine the involved structures, is usually the initial imaging of choice.[175] This may be followed by upper gastrointestinal series, a barium enema, a computerized tomography scan, cystoscopy, or an intravenous pyelogram depending on the presenting symptoms. Once

Box 19.14 Commonly Occurring Complications Associated with Fistulas

- Sepsis
- Malnutrition
- Fluid and electrolyte imbalance
- Anemia
- Acid–base imbalances
- Tissue destruction
- Pain
- Delirium

Table 19.16 Characteristics of fistula effluent

Fistula type	Effluent color	Daily output	pH	Components
Colocutaneous	Brown, tan	1–1.5 L/day	6.8–7.8	Water, mucous, sodium, potassium, and bicarbonate
Enterocutaneous	Bilious, tan, beige	7–8 L/day	6.5–7.5	Water, mucous, potassium, and bicarbonate
Pancreatic	Colorless	670–1000 ml/day	8.3	Water, bicarbonate, sodium, and potassium
Spit fistula (Esophagostomy)	Clear or color of fluids ingested	1–1.5 L/day	7.1–7.5	Water, mucous, amylase

Source: Adapted from Reference 174: Bryant RA. Anatomy and physiology of the gastrointestinal tract. In: Colwell JC, Goldberg MT, Carmel JE, eds. *Fecal and Urinary Diversions: Management Principles*. St. Louis: Mosby, 2004:33–59.

diagnosed, meticulous assessment is required to correct potentially distressing or even lethal complications. Comprehensive assessment includes nutrition and hydration status, vital signs, mental/cognitive status, pain assessment, inspection of the surrounding skin or wound bed, the quality and amount of fistula effluent, and electrolyte and acid–base evaluation. The effluent should be assessed for odor, color, consistency, amount, and pH.[175] Characteristics of the most common types of fistula effluent are displayed in Table 19.16.[174,180]

Palliative Fistula Management

Ostomy pouching techniques are the mainstay of palliative fistula management. Skin cleansing, skin protection, uneven skin surface management, dressing or pouch selection, containment of output, and odor control are essential components to fistula management in those with terminal illness.[175,178] Table 19.17 offers management considerations based on fistula output, number of fistula tracts, and location. In addition to these considerations, the type of pouching system should be chosen based on effluent consistency

Table 19.17 Palliative fistula management

Fistula classification	WOCN consult recommended	Pouching/Containment system	Odor control
Low-output	No, unless odor is uncontrollable	Skin barrier/Skin deficit management Gauze dressings Foam dressings Pediatric pouches Colostomy caps (small closed-end pouches)	Gauze dressing with charcoal Silver foams Pouching Pouch change in a well-ventilated room
Moderate-output	Yes	Skin barrier/Skin deficit management Pouches that allow direct visualization and/or access through a valve or door Spit fistulas may benefit from pediatric pouching due to difficult-to-pouch locations Multiple fistulas may be amenable to saddlebagging[a] Enteroatmospheric fistulas may be amenable to troughing[b] or bridging[c]	Pouching Pouch change in a well-ventilated room Internal body deodorants: bismuth, charcoal, peppermint oil
High-output	Yes	Pouches that allow direct visualization and/or access through a valve or door High output pouching system Spit fistulas may benefit from pediatric pouching due to difficult-to-pouch locations Multiple fistulas may be amenable to saddlebagging[a] Enteroatmospheric fistulas may be amenable to troughing[b] or bridging[c] Negative Pressure Wound Therapy (NPWT) may be considered	Pouching Pouch change in a well-ventilated room Internal body deodorants: bismuth, charcoal, peppermint oil

[a] *Saddlebagging*: Cut fistula openings on the back of two or more cut-to-fit ostomy pouches, off-center. Cleanse skin with warm water, apply skin protectant and fill deficits with stoma paste. Apply ostomy pouches, adhered to each other in an overlapping "saddlebag" fashion.[181]

[b] *Troughing*: Line the skin surrounding the wound and fistula with a skin barrier wafer and seal the edge nearest the wound with stoma paste. Place thin film dressings over the anterior aspect of the wound, continuing down to the fistula orifice and posterior aspect of the wound. Then place a cut-to-fit pouch over the opening in the film dressing that exposes the fistula orifice.[181]

[c] *Bridging*: (Prevents fistula output from contaminating the wound site.) Build a "bridge" by consecutively layering small pieces of skin barrier wafers together until it is the same height as the depth of the wound. Using barrier past, adhere the skin barrier "wedge" to the wound bed near the fistula opening. Cut to fit an ostomy pouch around the fistula using the bridge to adhere the pouch. Dress the anterior aspect of the wound.[181]

Source: Adapted from Hollister Education. Ostomy care tips: Fistula management. 2016: http://www.hollister.com/~/media/files/pdfs–for–download/ostomy–care/hol_os_fistula–management–care–tips_na_883064-1016.pdf (accessed December 26, 2017); and Reference 181: Seaman S, Bates-Jensen BM. Skin disorders: Malignant wounds, fistulas, and stomas. In: Ferrell BR, Coyle N, Paice J, eds. *Oxford Textbook of Palliative Nursing, 4th ed*. New York: Oxford University Press, 2010:325–340.

and location.[175,181] Thick pasty output is better managed with a pouch that has an open end and clamp, thin watery effluent with a narrow spigot or tube.[181] Spit fistulas may be better managed with neonatal or pediatric pouches, as anatomical structures of the head and neck region present unique challenges. All pouches must be emptied frequently, when one-third to one-half full. WOC consultation for moderate- to high-output fistulas is important to select the appropriate containment system, train staff and caregivers, and contain cost in terms of supplies and human resources. WOC consultation is also necessary if negative pressure wound therapy (NPWT) is chosen for both fistula and wound closure in enteroatmospheric fistulas.

Pharmacologic Management

Management of fistula effluent may require pharmacologic interventions aimed at reducing gastric secretions, gut-slowing, and/or minimizing output.[177] Gut-slowing and decreasing the amount of effluent help maintain intact pouching systems and the integrity of perifistula skin and maximize the ability to use the gut for nutrition.[175,177]

Reduction of fistula effluent includes the use of histamine-2 receptor antagonists or proton pump inhibitors to decrease gastric acidity and the volume of secretions.[182] Gradual titration and stepwise addition of medications such as loperamide, diphenoxylate hydrochloride and atropine sulfate, codeine, tincture of opium, and octreotide may reduce fistula output and slow gastrointestinal motility.[177]

Somatostatin is a hormone produced in the hypothalamus and other regions of the brain[182] that inhibits the secretion of nearly all alimentary hormones, thereby enhancing absorption of fluids and electrolytes and inhibiting secretion of gastric acid, pepsin, and bile.[182] In some studies, somatostatin analogues, such as octreotide, have been shown to decrease overall fistula output.[182] The efficacy of the role of somatostatin analogues in enterocutaneous and pancreatic fistula closure is, however, inconclusive.[182] Sufficient evidence does exist to use octreotide on a case-by-case basis for patients with moderate- and high-output fistulas.[182] WOC nurse consultation is recommended when considering the use of octreotide, typically given subcutaneously as 100 mcg every 8 hours over at least 7 days.[182,183] The WOC nurse will monitor for both efficacious and adverse effects, such as abdominal discomfort, nausea, flatulence, diarrhea, and steatorrhea.[183]

Nutrition Management

Nutritional support and fluid and electrolyte balance are essential components of fistula management. Malnutrition, dehydration, and electrolyte imbalances should be addressed based on the patient's preferences and goals of care. The gastrointestinal system should be used whenever possible for nutritional support, but intravenous fluid, parenteral electrolyte replacement, and total parenteral nutrition (TPN) may be necessary. If nutrition can bypass the fistula site, absorption and tolerance are better with use of the intestinal tract, but this isn't always possible.[181] Feeding via the fistula itself, termed *fistuloclysis*, has been documented using a 14-French tube and semielemental (partially digested) tube feeding formula.[177] WOC nurse and registered dietician consultation is recommended for all patients who warrant fistuloclysis or parenteral nutrition therapy.

Comprehensive management of fistulas in the patient with advanced or terminal disease requires an interprofessional team approach guided by a specialist-level WOC practitioner. Odor and effluent containment, perifistula skin protection, and maintenance of adequate nutrition and hydration combined with the prevention of sepsis, anemia, acid–base and electrolyte imbalances, pain, and delirium are essential in maintaining QOL.

Case Study: Resolution

The WOC nurse was consulted by the hospice team. She used a "crusting" technique (layering no-sting skin protectant with stoma powder) to cover the denuded skin and create a dry surface for the skin barrier to adhere to. She then chose a flexible one-piece pouching system that would fit the newly rounded contours of the patient's abdomen. She instructed the nursing staff on the pouch changing regimen (wear-time goal is 24–45 hours) and the importance of emptying the pouch when it was one-third full to avoid tension on the skin barrier. She recommended premedication with a short-acting opioid 20–30 minutes prior to the pouch change as part of pain management. The WOC nurse also suggested octreotide 100 mcg subcutaneously (through a subcutaneous line) every 8 hours over 7 days to slow and decrease the amount effluent. She educated the nurses on proper administration of octreotide and to monitor for side effects.

Urinary and Fecal Incontinence in Palliative Settings

Urinary and fecal incontinence management in palliative care balances advanced symptom control with minimally invasive, highly individualized interventions adapted to the terminally ill patient's progressive cognitive, psychomotor, and physiologic decline.

Incontinence and Quality of Life

Incontinence remains taboo in modern society and has a devastating effect on psychosocial well-being and QOL.[69,184] Incontinence in hospice and palliative care has many etiologies and can lead to shame, embarrassment, anxiety, depression, and social isolation.[71] Incontinence is a common impetus for institutionalization in the elderly and terminally ill.[69,185] Urinary incontinence also creates an extraordinary financial burden on patient and caregivers.[190] Caregiver strain associated with frequent incontinence care of a loved one is significant and can lead to multiple respite admissions and possibly long-term care placement. This may undermine the patient's goals of care if his or her wish is to die at home.

There is little published research about incontinence in palliative care and hospice settings. The focus of this section is the prevention and management of IAD. The most common types of incontinence or dysfunction encountered in hospice and palliative care, functional and transient urinary and fecal incontinence and urinary retention, and their management are discussed in Chapters 14 "Bowel Management" and 17 "Bladder Management in Palliative Care."

Incontinence-Associated Dermatitis

IAD is a form of irritant dermatitis that develops from chronic exposure to urine or liquid stool.[187] Repeated exposure to urine in the presence of occlusion or fecal material puts the skin at higher risk.[191] The skin has an "acid mantle," part of its protective barrier. The ammonia in urine is converted to ammonium by fecal bacteria which raises the skin's pH to alkaline.[188]

Prevention and Management

Prevention starts with the least invasive containment products (absorptive products, fecal pouches, condom catheters, female urinals), although more invasive strategies (indwelling Foley catheters, fecal management systems) may be considered on a case-by-case basis.

Perform incontinence care after each episode and daily with a pH-balanced, no-rinse cleanser.[187] Care should be taken to check closely in skin folds and not to scrub the skin vigorously. A skin moisturizer with humectants and emollients should be applied after cleansing and a skin barrier applied to protect the skin.[87] See Table19.2 for skin protectant options. For denuded or inflamed skin, implement the preventive steps, add a skin protectant, eliminate cutaneous candidiasis, and consider diversion of urine and/or stool using one of the aforementioned strategies.[188]

Conclusion

WOC maladies contribute to suffering and diminished QOL. Lawton observed that certain nursing interventions and adequate symptom management could once again "bind" the body, alleviating suffering and palliating the dying patient and his or her family's psychological distress.[69] In addition to a methodical, evidence-based approach to nursing care, this chapter highlights the dearth of research in palliative WOC care and the need for rigorous studies. Evidence-based palliative interventions combined with expert WOC nurse consultation is the key to providing high-quality palliative care and alleviating the multidimensional suffering experienced by patients and families at end of life.

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CHAPTER 20

Pruritus, Fever, and Sweats

Angel Smothers

Key Points

- Pruritus, fever, and sweats can decrease the quality of life for a patient living with a serious chronic illness.
- Both nonpharmacological and pharmacological interventions could improve these symptoms for patients.
- The underlying pathophysiology for all three symptoms is multifaceted and complicated.

Introduction

Palliative care is at the root of good nursing care. The Hospice and Palliative Nurses Association (HPNA) endorses the definition of palliative care originating from the National Consensus Project for Quality Palliative Care (NCP), which states: "Palliative Care means patient and family centered care that optimizes quality of life (QOL) by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing the physical, intellectual, emotional, social, and spiritual needs and [facilitating] patient autonomy, access to information, and choice."[1] Care of the patient with a serious chronic illness is multifaceted and includes both pharmacological and nonpharmacological interventions. The symptoms that are experienced by patients who are living with serious chronic illness can vary depending on the diagnosis as well as treatment plan for their diagnosis.[2] There are times when symptoms result from a disease, but there are also times when they occur as a side effect of a medication or other treatment modality. Because each patient's response to a serious chronic illness is unique, it is important to have a broad understanding of what the research shows as being effective in the management of symptoms.

In this chapter, emphasis will be placed on three of the symptoms that are commonly seen in patients who are living with serious chronic illness. Symptom presentation is unique in each patient and can occur individually but also can occur simultaneously. There is evidence to support the occurrence of a new symptom in response to the treatment of another symptom.[2] This vicious cycle often results in the discontinuing of a treatment modality or adding another treatment that results in other symptoms. By having a strong knowledge base of the underlying reasons for a symptom, the nurse can help select the best treatment option that will also result in the least number of negative sequelae. Each common symptom—pruritus, fever, and sweats—will be examined individually and then collectively at the end of the chapter. For each of the symptoms, a case study will be included to assist in identifying the potential of treatment options.

Pruritus

Pruritus is defined as an unpleasant sensation that triggers the need for a mechanical response such as scratching, rubbing, or pressure.[3] This sensation can negatively impact QOL and impair sleep.[4] However, pruritus is itself not a disease but instead a symptom of a disease or of an alteration of physiological functioning of one or more of the body's regulatory systems. There are common underlying triggers for pruritus: alteration of liver or biliary duct function, alteration in urinary secretory function, malignancy, or human immune deficiency virus (HIV) or the pruritus could be medication-induced.[3] Pruritus can further be defined as peripheral (prurioreceptive) or central (neuropathic). When considering a peripheral cause, the nurse might identify sources such as dermatitis, insect bites, or other skin reactions that would result in itch. On the other hand, with neuropathic causes, identifying the source of the pruritus in nursing assessment is often more difficult. With a neuropathic cause, the underlying source is often renal, biliary, hepatic, or malignancy related.[5,6] There are additional sources of pruritus, with none of the sources being fully understood. Each of the potential sources will be reviewed in the following sections.

Nursing Assessment with Pruritus

Nursing assessment of a patient with the complaint of "itching" will focus on different aspects using the assessment process. The nurse would start with an assessment of the patient's subjective complaint. Then, he or she should ask probing questions, such as: "How long has this been happening? When did this start? Is there anything that makes it worse or better? Has this happened before? If so, what helped relieve it?"

Next, the nurse would do a visual assessment of the areas where the patient is complaining of an itch. Often the sensation is generalized, and the patient is not able to pinpoint a location.[4] The nurse would assess for peripheral or dermatological sources of the itch, including rash. Afterward, the nurse would discuss with the patient his or her past medical history to include medications, recent changes in the treatment plan, past medical diagnoses, and any changes in cosmetics, lotions, laundry detergent, or soap. Collecting as much information as possible on the patient's complaint will allow for a thorough report to the practitioner who will be potentially prescribing medication or other treatments for the patient.[5]

Case Study: A Hemodialysis Patient with Pruritus

Sarah was a 76-year-old patient who was admitted to the hospital post hemodialysis after a significant drop in her blood pressure and heart rate. Sarah had a long-term history of the following medical diagnoses: diabetes, hypertension (HTN), congestive heart failure (CHF), hyperlipidemia, and anxiety disorder. Sarah had been receiving hemodialysis 3 days a week for the past 4 years, after she developed end-stage renal disease (ESRD) related to her long-term uncontrolled diabetes. Sarah had a family history of type II diabetes and had struggled since the age of 38 with managing her glucose level. During her hospital stay, Sarah developed severe pruritus and multiple skin abrasions had resulted due to her constant scratching. Sarah stated the symptoms were causing her great distress and were altering her QOL due to lack of sleep.

The nurse consulted the palliative care team at the hospital where the patient was staying, and the following treatment plan was developed.

1. The underlying source of pruritus was most likely uremic in nature. Patient and family were provided education on this as the potential source of the itching.
2. Nonpharmacological interventions that are supported in the literature were implemented and included: Cool baths, aloe vera gel, and phototherapy. Medications that are supported in the literature as being helpful in the management of pruritus were reviewed. See Table 20.1.
3. After review of patient's current medication list, which already included gabapentin, it was determined the next medication to try would be cromolyn sodium.

Sarah was started on the nonpharmacological interventions as well as on cromolyn sodium and reported improvement in symptoms within 24 hours.

Nonpharmacological Treatment for Pruritus of Varying Origin

Research supports the use of nonpharmacological treatments as a part of a treatment plan for pruritus of any origin. Nonpharmacological treatments shown to be effective in the management of pruritus utilizing skin application include baby oil, aqueous gel with aloe vera, lotion with mud from the Dead Sea, and cream containing sericin.[7] There is some evidence to support the effectiveness of phototherapy, which involves an ultra-violet (UV) lamp; acupuncture by a trained acupuncturist; and thermal therapy using far-infrared radiation as nonpharmacological treatments for pruritus.[7] An additional study examined the effectiveness of aromatherapy and found it to be a viable management option.[8] Transcutaneous electronic nerve stimulation (TENS) units have some research support as an effective option for nonpharmacological management of pruritus of varying origins.[6]

Pharmacological Management of Pruritus of Varying Origins

Pruritus management in palliative care patients can be difficult due to the multiple underlying mechanisms that could be linked to the symptoms. The treatment plan is individualized since there could be overlapping reasons for the symptoms. Therefore, understanding medications that could help manage pruritus in the palliative care population is important. Table 20.2 shows classes of medications that have some research to support them as potential treatment options for patients with varying underlying reasons for pruritus.[9–16]

Table 20.1 Medications indicated in the treatment of uremic pruritus

Name of medication	Class of medication
Gabapentin (Neurontin)	Antiepileptic
Pregabalin (Lyrica)	GABA analogue
Nalfurafine (Winfuran): In clinical trials in US	Kappa-opioid receptor agonist
Cromolyn sodium	Mast cell stabilizer
Hydroxyzine (Vistaril)	Antihistamine
Sertraline (Zoloft)	Selective serotonin reuptake inhibitor(SSRI)

Pruritus of Uremic Origin

Uremic pruritus (UP) is a common symptom that has been reported in as many as 42–75% of ESRD patients.[16] For patients who have been adequately dialyzed, the report is the same. Pruritus of uremic origin can be acute, short, or chronic in duration.[13] The exact cause of pruritus of uremic origin is not well understood, but evidence supports the relationship between this symptom in ESRD patients and a chronic inflammatory response involving sensory neurons, specifically unmyelinated C fibers.[16] Some of these sensory nerves respond only to itch, while others respond to both pain and itch; thus, these systems are closely linked. Mediators that have been linked to this response include histamine, endogenous opioids, and serotonin.[13]

Pharmacological Treatments for Uremic Pruritus

Research has supported the effectiveness of pharmacological treatments in the management of pruritus. Because the underlying origins of pruritus are not well understood, the medications to treat it are based on potential underlying causes for the itching sensation in patients. Additional research is needed to assess effectiveness. Inui (2015) found that nalfurafine hydrochloride was an effective treatment for UP.[12] There is evidence that the upper motor neuron system plays a role in the development of pruritus in renal failure. While this medication has been approved for use in Japan, it is currently in clinical trials to be evaluated for use in the United States. Therefore, nalfurafine as a k-opioid receptor agonist may improve pruritus in these patients through binding the k-opioid receptors.

Gabapentin has been studied and identified as an effective treatment option for UP. Gabapentin is classified as an antiepileptic drug and has been successfully used for many years in the management of nerve-related symptoms including neuropathy, pain, and itch. Because there is a neuronal mechanism that has been identified as a potential source of pruritus, gabapentin has been studied and determined to be effective in managing pruritus of uremic origin.[6]

There is some evidence that mediators released from mast cells play a role in UP. Therefore, cromolyn sodium has been studied as a potential treatment for UP. This medication blocks mast cell degranulation and therefore leads to decreased release of histamine.[9] A study identified a potential role for the medication sertraline in the management of UP.[16] Other selective serotonin reuptake inhibitors (SSRIs) have been researched and shown to be effective

Table 20.2 Medications indicated in the management of pruritus

Class of medication	Name of medication	Indication
Histaminergic (antihistamines)[9–11]	Hydroxyzine (Vistaril)	Has shown effectiveness in management of pruritus in HIV patients. Prevents fixation on the surface of the histamine receptors.
	Ketotifen (Zaditor)	Prevents fixation on the surface of the histamine receptors.
Opioid antagonist[9,10]	Naltrexone (Revia, Vivitrol)	Found effective in managing pruritus of cholestatic origin. Prevents the activation of spinal neurons that can lead to pruritus.
K-opioid receptor agonist[9,12]	Nalfurafine hydrochloride (remitch): currently in clinical trials in the US. Approved for use in Japan.	Found effective in managing pruritus of uremic origin. Prevents the activation of spinal neurons that can lead to pruritus.
Serotonergic medications[9,12,14,15]	Ondansetron (5-HT3 antagonist) (Zofran)	Blocks the pathway that could lead to itch by inhibiting the neurotransmitter 5-hydroxytryptamine.
SSRI (selective serotonin reuptake inhibitor)[9,16]	Sertraline (Zoloft) Paroxetine (Paxil)	Has been shown to be effective in pruritus of any known cause. Increases the amounts of serotonin available extracellularly which can then bind to the postsynaptic cleft preventing the transmission of the itch sensation.
Antiepileptic[6,9]	Gabapentin (Neurontin) Pregabalin (Lyrica)	Has been found effective in managing pruritus of uremic origin. May inhibit the transmission of nociceptive sensations to the brain thereby suppressing pruritus.
Antibiotics[9]	Rifampicin (Rifadin)	Has an indication in the management of pruritus of cholestatic origin. May change the GI bacterial growth which may influence the absorption of pruritogens.
Immunomodulator[9]	Thalidomide (Thalomid)	May act as a peripheral and central nerve depressant.
Benzhydryl derivative[9]	Flumecinol (Zixoryn)	Has been shown to lower serum bilirubin so could be effective in the management of pruritus of cholestatic origin.
Anion exchange resin[9]	Cholestyramine (Questran)	Interrupts the enterohepatic circulation of bile acids and has therefore been considered a treatment for pruritus of cholestatic origin.
Mast cell stabilizer[9]	Cromolyn sodium	Works by preventing the release of substances in the body that cause inflammation. Has also been shown to reduce serum tryptase levels.
Leukotriene modifier[9]	Montelukast (Singulare)	Prevents the inflammatory response produced by leukotrienes.
Hormone/glycoprotein[9]	Erythropoietin	May work to lower the effect of the hormone on plasma histamine concentrations.
Binding agent[9]	Activated charcoal	May work to bind the agents that lead to uremic pruritus.
Topical antipruritic/alkaloid[9]	Capsaicin (activate component of chili peppers)	Targets the transient receptor potential vanilloid receptor and counteracts itch by activating pain neurons.
Immunosuppressant/ calcineurin inhibitor[9]	Tacrolimus (Prograf)	Works by suppressing the differentiation of Th1 lymphocytes and ensuing interleukin (IL)-2 production.
Local anesthetic[9]	Pramoxine hydrochloride (Caladryl)	May work by blocking sodium channels within the neuronal membrane, decreasing conduction.
Vitamins/herbal[9]	Ergocalciferol (Vitamin D_2, calciferol)	May have antipyretic effect in uremic causes of pruritus due to impaired vitamin D metabolism that can occur in dialysis patients.
	Nicotinamide (niacinamide)	May have antipyretic effect through its anti-inflammatory and histamine-release blocking action.
	Omega-3 fatty acids	Has been shown to reduce inflammation, free radicals, and leukotriene B-4 so could work in uremic pruritus.
	Turmeric (powder of *Curcuma longa L.*)	Curcumin, a substance in turmeric, has an anti-inflammatory effect.
	Zinc sulfate	May act as an antagonist of calcium and prevents degranulation of mast cells.

in UP but do require dose adjustment in ESRD. Sertraline appears to be a better option due to the limited need for dose adjustment with ESRD.[16]

Pruritus of Cholestatic Origin

There is evidence available supporting the use of medications to mitigate pruritus in patients with cholestatic pruritus (CP) (Table 20.3). Evidence supports the use of rifampin, which is a class of antibiotic, as a pharmacological treatment of pruritus. Because rifampin has been shown to induce detoxicating hepatic enzymes and, therefore, competitively inhibit the reuptake of bile acids, there is evidence to support that it would lead to a decreased rate of pruritus in patients with pruritus of cholestatic origin.[17] In addition, flumecinol, which is a benzhydryl derivative, has been shown to lower serum bilirubin levels and would limit the amount of pruritus in cholestatic cases.

Table 20.3 Medications indicated in the treatment of cholestatic pruritus

Name of medication	Class of medication
Rifampin (Rifadin)	Antibiotic
Flumecinol	Benzhydryl derivative
Naltrexone (Revia)	Opioid antagonist
Ondansetron (Zofran)	Selective 5-HT3 receptor antagonist

Naltrexone, an opioid antagonist, has indications based on evidence for the management of CP. A higher than usual dose may be indicated for better management; however, higher doses in a palliative care patient could bring about worsening pain so its use would need to be individualized for each patient.[9] There is limited support suggesting that the use of corticosteroids may have a potential benefit for CP.[18] Research supports the use of ondansetron as a potentially effective management strategy for CP, but additional studies are needed to support this as a viable option.[13]

Pruritus of HIV Origin

Pruritus in HIV patients can have varying and complicated underlying mechanisms. The prevalence of pruritus in this population can be as high as 45%.[19] A significant percentage of pruritus in this population is cutaneous in nature.[20] Limited research, including studies that consist of small numbers of subjects, provides some support for medications in the pharmacological management of HIV-related pruritus (HIVP). Hydroxyzine HCL, an antihistamine, has demonstrated some effectiveness in the management of HIVP. The anti-inflammatory effect of pentoxifylline, indomethacin, and triamcinolone may have some impact on HIVP as well (Table 20.4).[9]

Opioid-Induced Pruritus

For patients who require pain or dyspnea management with opioids, the risk of pruritus related to this treatment can be high. Although pruritus is common with opioid use, the intensity can range from mild to severe.[21] In mild cases, patients may get relief with nonpharmacological treatment but with more severe cases, pharmacological treatment may be indicated. Pharmacologic treatments that have evidence to support them include naloxone and nalbuphine. The primary mediator of opioid-induced pruritus appears to be the central mu-opioid receptors. Therefore, these medications could decrease the rate and severity of pruritus from opioid treatment. Naloxone is an opioid antagonist and could therefore improve pruritus from opioid use but could also lead to worsening pain. The route of administration could also be a potential barrier for the use of naloxone; therefore, more evidence is needed regarding the benefits of naloxone. However, nalbuphine is a partial opioid antagonist and has been shown to treat opioid-induced pruritus more effectively than naloxone (Table 20.5).[22]

Table 20.4 Medications indicated in the management of pruritus of HIV origin

Name of medication	Class of medication
Hydroxyzine hydrochloride (Vistaril)	Antihistamine
Pentoxifylline (Trental)	Vasodilator/anti-inflammatory; phosphodiesterase inhibitor
Triamcinolone (Kenalog)	Corticosteroid
Indomethacin (Tivorbex)	NSAID

Table 20.5 Medications indicated in the management of opioid-induced pruritus

Name of medication	Class of medication
Naloxone (Narcan)	Opioid antagonist
Nalbuphine (Nubain)	Opioid agonist-antagonist

Fever

Fever has been defined as an elevation of body temperature that is mediated by the hypothalamus in response to exogenous pyrogens and pyrogenic cytokines.[23] The underlying mechanism of fever can vary in individual patients, particularly in the palliative care population. Fever can result in emergency department (ED) visits and hospitalization in palliative care patients.[24] Patients who exhibit an elevated temperature must be evaluated for the underlying source for the fever.[25] A fever of unknown origin (FUO) is generally defined as an immunologically normal host with oral or rectal temperatures of 38°C or higher at least twice a week for more than 3 weeks with no identified cause.[26] A FUO can be broken down into four potential causative categories: infection, malignancies, noninfectious inflammatory disease, and other miscellaneous causes.[27] The category of noninfectious inflammatory disease has been linked to potential causes such as vasculitis and autoimmune, rheumatic, and granulomatous disorders.

A complete history and physical exam is needed to identify the source of the fever. A FUO in a patient with a malignant disease might be related to the malignancy or from an underlying infection. Fever is a common occurrence during malignancy, especially during chemotherapy.[28] There are times when the use of antibiotics would be of potential benefit for the palliative care patient by reducing painful urination and related symptoms. When this is the case, antibiotics could be offered to the patient as an option for palliation. In situations where the patient is actively dying, antibiotics would have no benefit and could potentially make things worse. The use of an antipyretic medication such as acetaminophen, ibuprofen, or aspirin could be of benefit for the patient with a fever even if the patient has entered the actively dying phase by reducing pain, diaphoresis, and discomfort.[29]

Nursing Assessment and Diagnostic Evaluation with Fever

The nursing assessment in a patient with fever starts with the history of the fever. Collecting information such as when the fever first started, how long it has been present, other related symptoms, and whether this has happened in the past could help with current and future management of the fever.[28] A general nursing assessment that include auscultations of the lungs and heart, skin assessment including any wounds, and assessment of edema and capillary refill could help to identify signs of infection or a source for the fever. Potential diagnostic tests that might aid in identifying the source of the infection include complete blood count (CBC), erythrocyte sedimentation rate (ESR), C-reactive protein (CRP), tuberculin test, blood culture, antinuclear antibody (ANA), stools cultures, and spinal tap. Some of the diagnostic tests could be considered minimally invasive, but a spinal tap could be considered a very invasive procedure.[29] The patient's overall status and goals of care should be considered before the more aggressive tests are planned. The question should be asked "Will the test change our plan for therapy?"

Case Study: Management of Fever in Relation to a Patient's Goals of Care

Mr. Markman was a 67-year-old man with a diagnosis of stage IV non–small cell lung cancer (NSCLC); because of the advanced stage, he was not a candidate for surgery. He had received chemo therapy for the past 6 months, with his last treatment a few days ago, yet recent scans revealed wide spread metastases to bone, liver, and brain, and he had been told by his oncologist that the treatment plan no longer includes chemotherapy. The patient was referred to hospice for home palliative care. Upon arrival at the home, the nurse found Mr. Marksman's temperature to be 40°C. He was not experiencing chills and had no other complaints. His pain was managed by oral oxycodone/acetaminophen (Percocet) 3 or 4 tablets per day. The nurse reviewed his past medical history and found diabetes, hypertension, and a smoking history of two packs per day for 50 years. Lab work demonstrated a normal CBC, ANA, ESR, CRP, and blood cultures.

The nurse provided assessment data including updated lab work to the hospice medical director who was overseeing Mr. Marksman's admission to hospice, noting that he had a chemo treatment a few days before. The patient confirmed that he sometimes had an elevated temperature after getting chemo. The patient was prescribed acetaminophen 500 mg every 6 hours for elevated temperature as needed. The nurse also asked the medical director to change the oxycodone/acetaminophen to oxycodone alone so as not to deliver doses of acetaminophen exceeding 2,000–3,000 mg/day.

Mr. Markman took the acetaminophen for 24 hours and his fever subsided.

Nonpharmacological Treatment Options for Fever

Evidence for nonpharmacological management of fever goes back many years. Some of the evidence-based nonpharmacological treatments for fever include fans, cool cloths to head and axilla, ice packs, drinking cool liquids, tepid water bath, and other treatments including a cooling blanket.[30]

Pharmacological Treatments for Fever

Pharmacological treatment for fever focuses on the use of antipyretic medications including acetaminophen, ibuprofen, and aspirin. In the palliative care patient, it is important to consider the potential methods for administration. For patients who have a fever and are not able to take medication by mouth, these medications can be administered by suppository.[31]

Sweats

The human body contains more than 4 million sweat glands that help to thermally regulate it. These glands are subdivided into three different types: apocrine, eccrine, and apo-eccrine.[32] There are two underlying types of sweating: emotional and thermoregulatory.[33] Thermoregulatory sweating is controlled primarily through the hypothalamus, and emotional sweating is controlled through the limbic system. Excessive sweating, referred to as *hyperhidrosis*, can be generalized or focal. When generalized, hyperhidrosis occurs in more than one location and can occur in any location where sweat glands are located. Focal hyperhidrosis is primarily seen in the axillae, hands, feet, and face. In the palliative care population, sweating could be related to either an emotional cause or be related to thermoregulation. Some of the common causes of sweating in palliative care patients include opioids, hormonal changes, and tumors. And since sweating often accompanies fever, many of the treatments for fever will, in turn, improve outcomes for a patient who is experiencing sweating.[33]

Nursing Assessment of Sweats

The nursing assessment of a patient who is experiencing sweating should focus on identifying the underlying cause. Some assessment data that should be collected during this nursing assessment include timing of the symptoms, temporal pattern, medication history, and changes in severity of symptoms.[33] Understanding that there are both emotional and thermoregulatory factors involved can help the nurse to ask probing questions during the assessment. Because both the limbic system and the hypothalamus can be involved with sweating, there may be an underlying neurological issue that is leading to the sweating, which could mean the sweating is unrelated to any fever that the person may have. Some common neurological issues might include stroke, seizure disorder, multiple sclerosis, and paralysis. However, sweating could be linked to fever; so therefore, when they are occurring together, the assessment of them should be made at the same time.[33] Nursing assessment should also focus on ways to improve the patient's comfort related to the sweating. Protecting the integrity of the skin is important and assessment for this would be a nursing priority.[34]

Case Study: Sweats that Can Alter the Course of a Chronic Illness Due to Decreased Sleep and Quality of Life

Rebecca was a 16-year-old patient who had a diagnosis of a malignant spinal cord lesion. The primary site of the malignancy had not been determined. The patient was being evaluated for symptom management by the acute care palliative care team. Rebecca complained of excess sweating of palms and back of the neck for the past week. She stated it kept her from sleeping, and she was reluctant to leave the house because of the sweating. On assessment, the patient had no fever, was alert, oriented, and ambulatory. The only other complaint she had was back pain around the lesion, pain controlled with oxycodone/acetaminophen.

The nurse's assessment findings were discussed with the palliative care team nurse practitioner to develop a treatment plan. Because of the lack of other related symptoms including fever, chills, signs of infection, or change in level of consciousness, the nurse practitioner felt the symptoms were neurologically linked. Since the sweating was focal in nature, the nurse practitioner prescribed a cream that included aluminum chloride 15%.

The patient's sweating lessened, and she returned to her regular routine including playing in her church band on Sundays.

Nonpharmacological Treatment Options for Sweating

For patients who are suffering with sweating, management should start with a conservative approach. The use of a technique called *tap* *water iontophoresis* has patients immerse their hands in cool tap water where electrodes are applied.[31] The goal of this nonpharmacological treatment for sweating is to disrupt the ion transport in the secretory tangle of the sweat glands and is primarily effective for excessive sweating in the palms or feet. More aggressive surgical options are available with the use of an endoscopic thoracic sympathectomy if the symptoms are progressive, debilitating, and altering the patient's QOL. Surgical removal of the sweat glands in a focal region of excessive sweating is another aggressive treatment option, one not likely to be used in the palliative care setting.[31]

Pharmacological Treatment Options for Sweating

For patients who do not respond to nonpharmacological options, the use of medications may be of benefit. These medications vary in response rate and underlying reason for effectiveness. Topical creams containing aluminum chloride 15–25% have been shown to be effective in focal areas of sweating.[32] The injection of botulinum toxin has evidence to support its effectiveness for focal sweating. This will inhibit the release of acetylcholine from the sudomotor synapses, which will limit the glands ability to secrete.[32] Anticholinergic medications, including glycopyrrolate and oxybutynin, are used for sweating due to their drying effect.[32] There is research that supports the use of antidepressants such as amitriptyline for decreasing sweating in the palliative care patient.[33] Finally, there is research to support the use of antihypertensive medications, such as beta blockers, calcium channel blockers (diltiazem), alpha blockers (phentolamine), and alpha 2 blockers (clonidine).[32,33]

Conclusion

Patients who experience pruritus, fever, or sweating often report impaired QOL. For the palliative care patient who may be approaching or currently is in the terminal phase of chronic illness, symptom management in a timely manner can be enhanced using evidence to guide practice.[34] More research is needed to better understand the mechanisms of pruritus, fever, and sweating along with appropriate and effective interventions.[35,36] This includes the need for improved research on the nonpharmacological interventions to treat these symptoms.[37] The significance of these symptoms must not be underestimated in the patients who experience them.

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CHAPTER 21

Neurological Disorders

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Key Points

- All patients are at risk of developing neurologic complications of their diseases.
- Many neurologic diseases are incurable and will result in a high symptom burden.
- Palliative care nurses must be alert to these possibilities and knowledgeable about management.

Introduction

The palliative care nurse is likely to encounter a patient with advanced neurological disorder or with a medical condition with neurological complications. It behooves the palliative care nurse to prepare for the variety of symptoms and diagnoses that he or she will clinically encounter. This chapter aims to lead the palliative care nurse to the appropriate, evidence-based interventions for the patient with neurological disturbances. We will address broad symptom categories as well as common neurological diseases with heavy symptom burden deserving of special attention.

Abnormal Movements

The human body is capable of a broad variety of involuntary and abnormal movements—shivering, tremor, seizures, fasciculations, myoclonus, and chorea to name a few. See Table 21.1 for definitions of the abnormal movements most frequently encountered. Although it is beyond the scope of this chapter to delve into all of the possibilities, we will review those most relevant to the practice of the palliative care nurse.

Seizures

> "I woke up to Frank saying 'ah, ah, ah' in his sleep. Then his breathing changed and his arms went up to his chest. After a minute or two he started shaking all over. I called 911. By the time they got here it was all over. He was confused for an hour in the ER."
>
> —A wife describing her husband's first seizure

Seizures are defined as electrical discharges of the cerebral cortex with resulting changes in the functions of the central nervous system (CNS). For an aberrant electrical phenomenon to propagate and result in a seizure, three physiologic conditions must exist: neurons capable of undergoing excitation, capacity for spread of the electrical phenomenon to surrounding neurons, and diminished ability of gamma-aminobutyric acid (GABA)-nergic neurons to suppress excitatory events. Any condition that disturbs the normal environment of the CNS can result in a seizure. Thus, any given patient has the capacity to experience a seizure. There are a number of conditions that increase the risk of an epileptic event. Most common are acute metabolic derangements, medications and substances, space-occupying lesions of the brain, ischemic events, and infection (see Tables 21.2 and 21.3). It is important to note that a single seizure does not constitute epilepsy.

Witnessing a seizure can be a traumatic event for caregivers and providers. Additionally, the emotional burden for patients with seizures is great. The impact of seizures on health is enormous—an estimated 50 million people worldwide have epilepsy. The incidence of a single unprovoked seizure event is estimated to be between 23 and 61 per 100,000 person-years.[1] Research on patients with epilepsy and their caregivers reveals persistent societal and individual stigma associated with this disorder and the resulting seizures.[2] Patients with epilepsy are at higher risk of impaired sleep, mood disorder, pain, social withdrawal, and psychological distress.[3,4] Unchecked, seizures can result in significant morbidity—delirium, physical injury, aspiration, rhabdomyolysis and renal injury, pain, temporary paralysis, and loss of function. Among oncology patients there are a number of factors increasing the risk for seizures. Brain metastases, chemotherapy, and radiation, as well as metabolic and endocrine changes in the patient with cancer increase the risk for seizures. In patients with primary brain tumors, the burden of seizures is staggering. Estimates of the prevalence of seizures in this group vary across specific tumor histology. The financial, emotional, and social burden of seizures is also an important consideration. There are many interventions available to the palliative care nurse to reduce the impact of seizures.

The palliative care nurse begins with a careful history and physical exam. Any new physical findings may suggest an underlying physiologic change that has lowered the seizure threshold. Recent medication changes require careful review as these changes are frequently implicated in new-onset seizures. In patients with primary brain tumors or intracranial metastatic disease, seizures are generally a result of edema and blood–brain barrier disturbance, mass effect, and cortical involvement. Additionally, the patient entering inpatient or hospice care with a history of substance abuse is at elevated risk for seizures if the patient is newly abstinent from alcohol, benzodiazepines, opioids, or illicit substances. If no source is immediately identified, radiographic or metabolic evaluation may be indicated if it is within the goals of care.

Family and patient teaching are important to dispel fear and to maximize patient comfort. Education goals focus on safety during seizures, postictal care, medications, eliminating the cause of the

Table 21.1 Commonly encountered neurologic definitions

Agraphia	Inability to write. Of note, agraphia rarely occurs in isolation.
Akathisia	A sensation of restlessness, often accompanied by a compulsion to move the effected limbs. Most commonly found in patients with Parkinson's disease, dementia, and those receiving neuroleptics.
Alexia	Inability to read.
Aphasia	Impaired verbal or written communication because of an acquired insult to the brain. Expressive aphasia is an impairment in the ability to generate spoken language (also known as anterior/nonfluent/Broca's/motor aphasia). Receptive aphasia is difficulty or inability to understand spoken word (also known as posterior/fluent/Wernicke's/sensory aphasia). Global aphasia is the inability to utilize language. Patients with global aphasia can neither read nor write.
Asterixis	Also known as "flapping tremor," asterixis is commonly encountered in patients with metabolic and toxic encephalopathy (most notably in ammonia-retention). It is characterized by irregular lapses of a sustained posture, often followed by an overcorrection. It is also observed in neck and arms of the drowsy person.
Ataxia	Lack of coordination of voluntary movements.
Athetosis	Involuntary and abnormal slow, complex writhing movements. Most commonly involves fingers, hands, toes, and feet. Encountered in various forms with encephalitis, hepatic encephalopathy, Parkinson's disease, Huntington's disease, and cerebral palsy.
Chorea	Arrhythmic movements characterized by a writhing, rapid, and jerky quality. The movements are purposeless and involuntary. Often accompanied by a general state of hypotonia—the limbs hang slack. The major distinguishing feature of Huntington's disease.
Clonus	Rhythmic contraction and relaxation of antagonistic muscle groups.
Corticospinal tracts	The neurons connecting the cortex of the brain (gray matter) with the lower motor neurons in the ventral horn of the spinal cord.
Dysarthria	Impaired speech output due to oral, lingual, or pharyngeal motor impairment.
Dyskinesia	A wide-encompassing term meaning abnormal movement. Movements can be intermittent or persistent. In tardive dyskinesia, the movements are slow, rhythmic, and automatic.
Dysmetria	Ataxia with overshoot or undershoot of movement, dysmetria results from difficulty processing or perceiving the position of the body in relation to its surroundings.
Dysphagia	Impaired ability to swallow in a coordinated and timely fashion.
Dystonia	A unilateral movement defined by involuntary muscle contraction of both the agonist and antagonist muscles. The result is the limb held in a twisted, distorted posture. Can affect a limb, the head and neck, the face, or the spinal muscles.
Fasciculation	A small, localized pattern of muscle contraction and relaxation, often observable through the skin. Commonly noted in the eyelid of healthy individuals, it can also be seen in ALS, progressive spinal muscle atrophy, or in states causing nerve fiber irritability (dehydration, muscular exhaustion, and metabolic imbalance).
Lower motor neuron	The neurons that connect the upper motor neurons to the muscle fibers. Lower motor neurons originate in the ventral horn of the spinal cord or in the brainstem motor nerve nuclei and terminate on the neuromuscular plate of effector muscles.
Myoclonus	Rapid and irregular shocklike contractions of a group of muscles. The most commonly experienced myoclonic events are hiccups and "sleep starts." Palliative care nurses are likely to encounter opioid-induced myoclonus.
Myokymia	The irregular firing of several motor units, seen as a rippling of the skin.
Nystagmus	Involuntary jerking movement of the eyes in either a lateral or vertical direction.
Opsoclonus	Involuntary and irregular multidirectional movement of the eyes.
Seizures	Aberrant electrical activity of a part or the entire cortex of the brain, resulting in altered neurological functions.
Tardive dyskinesia	A specific dyskinesia characterized by repetitive and stereotyped movements often of the face, mouth, and tongue. It is most commonly an effect of antipsychotic medications.
Tremor	Rhythmic contraction of a muscle or group of muscles in opposing directions.
Upper motor neuron	The motor neurons originating in the motor cortex of the brain or brainstem and carrying synapses down to the lower motor neurons. Upper motor neurons do not directly contact the target muscle.

seizure when feasible, and determining when to contact the provider. Safety during a seizure focuses on minimizing injury—falls and physical trauma during clonic movements as well as minimizing the length of the seizure if possible. Padding the patient's surroundings (bed rails) is traditionally done in patients with refractory seizures. Although a prudent intervention, no data exist to support this long-standing nursing intervention. See Box 21.1 for seizure first-aid and safety suggestions. Placing objects in the mouth and restraining the patient are absolutely contraindicated. Patients should not be given food or liquid until they have fully recovered consciousness. Should the patient fail to regain full consciousness between seizures or continue to seize after several minutes—a

Table 21.2 Common conditions resulting in seizures

Metabolic changes	Electrolyte imbalances Thyrotoxic storm Uremia Hypertensive encephalopathy Hypertension of pregnancy (eclampsia and preeclampsia) Fever Dehydration and overhydration Hyperventilation
Medication-related, illicit substance-related	Missed doses/withdrawal New medications Metabolite accumulation
Intracranial tumors	Metastatic tumors Primary central nervous system tumors
Ischemia	Stroke Diffuse cerebral hypoxia
Infections	Encephalitis Meningitis Intracranial abscess Parasitic lesions
Paraneoplastic syndromes	NMDA-receptor encephalitis
Trauma-related	Subdural hematoma Subarachnoid hemorrhage Intraventricular hemorrhage Trauma-induced gliosis Post-traumatic epilepsy
Vascular lesions	Atriovenous malformation Intracranial aneurysm Subdural hemorrhage or fluid collection Epidural hemorrhage Subarachnoid hemorrhage
Idiopathic or congenital disorders	Birth injury Congenital malformation Enzyme deficiencies Lysosomal storage disorders Channelopathies

condition known as *status epilepticus*—urgent action is required. Status epilepticus is treated as a serious and life-threatening situation requiring immediate administration of medication to break the seizures. If the seizure occurs in the home, emergency medical services may be appropriate if consistent with the goals of care. Of note, there remain several states in the United States that require providers to report seizure events to the Department of Motor Vehicles. Certainly, patients with seizures should abstain from driving until cleared by a neurologist.

Of utmost importance for patient comfort and safety is to stop the seizure as it happens. Seizure-ablative medications may be limited by the specific patient situation. The patient receiving hospice at home will likely be best served by administration of rapid-acting benzodiazepines. Orally administered concentrated lorazepam drops are readily available from the hospice pharmacy. Other choices include rectal diazepam gel, nasal lorazepam gel, or clonazepam wafers applied to the buccal surface. In the patient with intravenous access, slow intravenous push administration is generally the preferred choice. The patient with significant risk of seizures, a history of status epilepticus, or currently on antiepileptic seizure medications is well-served by an at-home seizure management plan. Particularly for patients with complex seizure management, a seizure management plan is developed in concert with the neurologist. This intervention offers the patient, family, and caregivers peace of mind and a sense of agency in the face of a potentially terrifying event. The National Health System in the United Kingdom is trialing a protocol to provide patient, family, and caregiver training for seizures in an effort to improve home management and family/caregiver confidence in managing seizure and to reduce emergency room visits and medical costs.[5]

Several issues require specific attention in the palliative care setting. In a patient with a reversible condition, antiepileptic drugs (AEDs) may not be required. Patients with epilepsy or significant risk for ongoing seizures will require careful consideration for AED choice. If the patient with metastatic or primary brain tumors has never experienced a seizure, the current recommendation is not to prophylactically administer anticonvulsants.[6] For a brief overview of factors to be considered when introducing AEDs, see Box 21.2. Notably, several choices have arisen in recent years for the patient with medically refractory seizures. A restrictive diet inducing a ketogenic state has been studied for decades for medically refractory childhood epilepsy with some success.[7–9] Surgical options include resection of the seizure focus or lesion as well as vagal nerve stimulator placement.[10–13] Careful consideration must be given to the life expectancy and appropriateness of the patient for such procedures and interventions.

Seizures at the end of life are a concern for all terminally ill patients. When patients have lost the ability to swallow, seizure management of multi-drug AED regimens may require careful tailoring to the situation. Several interventions have been tried and small case series have been published. However, there is no universally accepted management protocol, and the hospice team may need to be creative. Subcutaneous levetiracetam administration in end-of-life (EOL) care has been reported in a United Kingdom trial.[14,15] However, randomized controlled trials do not yet support the integration of this route into standard of care.

Myoclonus

Case Study: A Pediatric Patient with Opsoclonus-Myoclonus Syndrome

Franklin was just a few years old when his mother noticed his balance was off. Then she noticed his "fits"—he was unable to walk, his trunk and limbs would jerk randomly, and his eyes seemed to dance around. Ultimately, Franklin was found to have opsoclonus-myoclonus syndrome from an autoimmune response to a neuroblastoma tumor in his abdomen. With treatment, the fits stopped.

Myoclonus is a series of brief muscular contractions. The contractions are irregular in both the amplitude of contraction and rhythm, and it denotes a disturbance of the CNS. There are a wide variety of myoclonic syndromes. In the palliative care setting, the nurse is

Table 21.3 Seizure definitions

Simple focal (partial) seizure	The uncontrolled electrical activity in a simple partial seizure is limited to a small area of the cortex. The resulting seizure is not accompanied by loss of consciousness. Symptoms include shaking of a single area of the body. Less commonly, simple partial seizures can result in abnormal sensations of the affected limb or in abnormal sensations such as auditory, visual, or gustatory changes. Rarely, simple partial seizures can result in behavior and emotional changes.
Complex focal (partial) seizure	Affecting a larger area of the brain, complex partial seizures result in impairments in the ability of the person to interact with his surroundings. Often starting with a blank look or staring spell and progressing to stereotyped, repetitive movements. Also termed "psychomotor seizures."
Generalized seizure	The most common and obvious of the seizures. Generalized seizures involve the entire cortex of the brain. The typical generalized seizure begins with limb stiffening (tonic posturing) and a period of apnea or hypoventilation. This gives way to clonic movements (jerking of the limbs and/or head as muscles contract and relax together). During the clonic phase, breathing returns although it is often irregular.
Absence seizure	A generalized seizure in which the patient abruptly ceases activity and stares blankly. The patient is unable to interact with his environment during the seizure. As soon as the seizure is finished, the patient returns to the activity preceding the ictal event.
Atonic seizure	Atonic (drop-attack/astatic/akinetic) are generalized seizures resulting in an abrupt loss of postural tone. Loss of tone can vary from head drooping to full collapse.
Aura	In epilepsy, an aura is the initial phase of a focal seizure. It is generally experienced as a motor, sensory, autonomic, or psychic event. For some patients, the aura alone constitutes the seizure.
Epilepsy	A syndrome of repeated seizures.
Febrile seizure	A seizure occurring in infants and children (ages 6 months to 5 years) in the setting of a temperature usually above 38°C. Febrile seizures are usually a single generalized motor seizure as the patient's temperature peaks. Be certain to distinguish between febrile seizures and complicated febrile seizures, the latter occurring repeatedly during a febrile illness.
Ictal	Latin for "stroke," ictal has come to mean the height of a seizure or migraine.
Psychogenic nonepileptic seizures	Also called "pseudoseizures," these are events characterized by changes in neurological function in the absence of electroencephalographic changes indicating abnormal electrical activity of the cortex.
Status epilepticus	A cluster of seizures without return to full neurological baseline between events or a single, ongoing seizure lasting more than a few minutes. Considered a medical emergency, status epilepticus carries an elevated risk of brain damage, hypoxia, and death.

Box 21.1 Seizure Safety

Seizure First Aid

Prevent injury by moving furniture or hard objects out of the way

Refrain from putting anything in the mouth of the patient

Place a pillow or soft item under the patient's head

Loosen tight clothing around the neck

After-Seizure Care

Avoid situations dangerous to the epileptic (open flame, unaccompanied boating/swimming/tub-bathing)

Avoid seizure triggers (sleep deprivation, blood sugar lows, alcohol consumption, and excess caffeine intake)

most likely to encounter diffuse myoclonus rather than myoclonus simplex or segmental myoclonus. See Table 21.4 for other causes of myoclonus. Diffuse myoclonus is characterized by random jerks, widespread throughout the body. It can be either a passing or persistent phenomenon. Myoclonus has gained increasing awareness in the palliative care setting as it can lead to increased pain, fatigue, and other distressing symptoms. Intervention begins with recognizing the causative factors. The palliative care nurse is most likely to encounter diffuse myoclonus from acquired neurologic disease or metabolite accumulation. Several other causes of myoclonus are known: epileptic, hereditary (sometimes called essential or familial), immune, and toxic disorders. Myoclonus also occurs in some forms of degenerative neurological disorders.

The palliative care nurse begins with careful examination and review of medications. An interview of the patient and family may elicit a recent change. Renal impairment is associated with opioid-induced myoclonus (OIM). The patient or family will describe nonrhythmic jerking movements. Stimulation of the patient or tapping on the muscles may bring on or worsen myoclonus. Hyperalgesia and hallucinations in the setting of myoclonus raise the suspicion of OIM and should trigger an evaluation of pain medications. In the patient with opsoclonus-myoclonus syndrome, the myoclonus is typically diffuse or focal with titubation (rhythmic tremor of the head or trunk). Ataxia and other cerebellar symptoms may also be apparent. The diagnosis of opsoclonus-myoclonus is based on clinical, serological, and radiographic testing. In the palliative care setting, the goals of care are always considered when deciding whether to conduct this testing.

Elimination of the causative factor, if possible, is most likely to induce remission of the myoclonus. In the patient on opioid medications, opioid rotation is indicated. The precise mechanisms behind OIM are unknown. The leading theorized mechanism points to accumulation of neuroexcitatory metabolites, particularly hydromorphone-3-glucuronide and morphine-3-glucuronide in the setting of impaired kidney function.[16] Although higher doses of opioids are more commonly implicated in OIM, it can occur in patients with relatively low doses and preserved renal function. Opioids implicated in OIM in the literature include morphine, hydromorphone, fentanyl, methadone, and meperidine. If OIM is

Box 21.2 Special Considerations when Introducing an Antiepileptic Drug (AED)

Drug interactions are common with AEDs, especially older generation medications that induce the cytochrome P450 hepatic enzymes

Many AEDs can alter mood and are used as psychotropic medications

Carefully review comorbidities; for example, phenytoin can cause osteoporosis, topiramate can induce weight loss

In the patient with limited life-expectancy, impaired level of consciousness or diminished ability to swallow make most oral AEDs poor choices—consider scheduled benzodiazepines

Most AEDs do not require drug level monitoring

Dexamethasone is neither an antiepileptic medication nor a seizure-ablating drug

Phenytoin increases metabolism of corticosteroids, and corticosteroids can alter the metabolism of phenytoin—consider a different AED

Consultation with a neurologist may be warranted

Table 21.4 Etiologies of myoclonus

Drug-related	Opioid-induced myoclonus (OIM) Lithium toxicity Haloperidol Phenothiazines Cyclosporine Beta-lactam antibiotics Antidepressants
Metabolic disorders	Hepatic encephalopathy Nicotinic acid deficiency Uremia Storage diseases
Inflammatory disorders	Thyroiditis
Infectious diseases	Whipple disease of the central nervous system Tetanus Herpes zoster myelitis
Central nervous system disorders	Hypoxic brain injury Multiple sclerosis Paraneoplastic syndromes AIDS dementia complex Viral encephalitis Advanced dementias Cerebellar degenerative conditions Basal ganglia degenerative conditions Creutzfeldt-Jakob disease Parkinson's disease Subacute sclerosis panencephalitis Myoclonic epilepsy syndromes

suspected, opioid rotation, addition of a benzodiazepine such as clonazepam or midazolam, and a trial of adjuvant medications are indicated.[17]

Treatment of non-OIM myoclonus includes eliminating causative conditions. Few medications have been found to ease myoclonus. Anticonvulsants can be helpful in chronic myoclonus, although typically multidrug therapy is needed. Clonazepam is the most frequently used and most effective agent. Other drugs have been tried, including valproic acid, levetiracetam, zonisamide, acetazolamide, and sodium oxybate, although strong data for each of these medications are lacking.[18] Several non-AEDs have been tried for myoclonus, including baclofen and dantrolene, also with varying success.

Nursing-specific care for myoclonus is multifaceted. Safety takes priority. Padded side rails and helmets may be necessary. For patients with severe myoclonus, ambulation may not be possible. Physical or occupational therapy assessment will determine whether durable medical equipment, assistive devices, or a gait belt are needed. Offer strategies for safe patient transfers to families and caregivers. As with all palliative care measures, assessment for pain is necessary. During opioid rotation, the risk for discomfort is high because of variability in cross-tolerance. Myoclonus is fatiguing. Teaching patients and family members energy conservation is important. Myoclonus increases caloric expenditure, and, in the medically frail patient, nutritional supplementation or counseling may prevent weight loss. Provide a low level of stimulation (low light, minimizing noise).

Spasticity

Case Study: A Patient with Spasticity

Keira was in a car accident as a young woman. She suffered head trauma with a hemorrhage in the deep white matter of the right hemisphere of her brain. Keira was unable to move the left side of her body. With therapy, she regained some movement on the left but was left with increased muscle tone and spasms. Her physiatrist assesses her yearly—the spasms and hypertonicity make fine motor tasks more difficult but allow her to walk without any assistive devices.

Spasticity is increased muscle tone to the extreme. It results from denervation of muscles or from demyelination of neurons in the CNS—typically because of a lesion of the upper motor neuron (UMN). Spasticity occurs in many neurologic conditions. It is commonly encountered with spinal cord injury, multiple sclerosis (MS), cerebral palsy, stroke, brain or head trauma, amyotrophic lateral sclerosis (ALS), hereditary spastic paraplegias, and metabolic diseases.

The most sensitive indicator of an UMN lesion is a positive Babinski sign. It is elicited by firmly stroking the lateral plantar surface of the foot. A positive Babinski sign is extension of the large toe accompanied by fanning and extension of the other toes during and immediately after the stimulus. The Babinski sign mimics the physiologic reflex observed in infancy. Spasticity shows a predilection for antigravity muscles: brachialis, brachioradialis, biceps, pectoralis, anterior deltoid, and the flexor carpi muscles of the arms as well as the hip flexors, gastrocnemius, hamstrings, and popliteus muscles of the legs. Other physical exam signs include hyperreflexia of the deep tendon reflexes, clonus, muscle spasms, and scissoring of extremities. Spasticity can occur in any muscle or muscle group. One notable example is the spasticity and dystonia of cranial nerves in bulbar or pseudobulbar palsy.

Spasticity can be uncomfortable and painful. It can also severely limit functional abilities and thus requires considered treatment. The palliative care nurse will consider whether the condition is established spasticity with worsening, as with our case study. In this situation, the nurse will seek secondary causes—infection, constipation, pain, or autonomic dysreflexia. If the spasticity is new, further investigation is required. In a patient with MS, the primary concern is for disease progression. It is imperative to balance spasticity with the functional abilities of the patient. For example, the patient with spastic cerebral palsy must preserve some muscle tone in order to ambulate.

Many treatments are available for spasticity. Research into the neurochemical changes of spasticity has demonstrated that glutamic acid is the primary neurotransmitter of the corticospinal tracts. Baclofen, a GABA derivative, is the mainstay treatment. Other commonly used oral antispasmodics include dantrolene, diazepam, and tizanidine for the desired effect of diminished force of contraction. Spasticity is one of the few generally agreed on medical uses for marijuana.[19–21] See Table 21.5 for a summary of oral antispasmodic medications. Phenol and botulinum toxin are injected for patients with persistent spasticity and torticollis. Surgical interventions are also available for the patient with medically intractable spasticity. Intrathecal administration of baclofen has become a mainstay of treatment for patients with persistent spasticity with significant side effects from oral baclofen.[22] These

Table 21.5 Medications used to treat spasticity

Drug name	Mechanism of action	Most common use	Common side effects
Baclofen	Inhibition of synaptic reflexes at the spinal cord level	Spasticity Hiccups	Central nervous system (CNS) depression, weakness, hypotension, gastrointestinal (GI) disturbance, polyuria
Carisoprodol	Unknown	Spasticity Muscle pain due to injury Adjunctive to opioids—use carefully in combination with any CNS depressant, especially synthetic opioids	CNS depression, idiosyncratic reactions of weakness and euphoria, seizures
Chlorzoxazone	Reduces polysynaptic reflexes	Muscle spasm and pain	Withdrawal if abruptly discontinued, CNS depression, paradoxical stimulation, GI disturbance, rash, hepatotoxicity, hypersensitivity reaction
Cyclobenzaprine	Unknown	Spasticity	CNS depression, dry mouth, dizziness, agitation
Dantrolene	Local action on the excitation-contraction units of the muscle	Spasticity Malignant hyperthermia Serotonin syndrome "Ecstasy" intoxication	CNS depression, hallucinations, hepatotoxic effects, GI disturbance
Diazepam	Reduced neuronal excitability via enhanced GABA-ergic inhibition	Agitation Alcohol detoxification Anticonvulsant Anxiolysis Spasticity Sedation	CNS depression Anterograde amnesia Psychiatric disturbance Seizures if acutely withdrawn Abuse
Gabapentin	Reduced neuronal excitability via enhanced GABA-ergic inhibition	Anticonvulsant Neuropathic pain Spasticity	CNS depression, dizziness, weight gain, fatigue, peripheral edema, risk of suicidality
Orphenadrine	Anticholinergic	Low back pain, sciatica Adjuvant treatment of neuropathic pain and spasticity	CNS depression, dry mouth, dizziness, restlessness, insomnia, constipation, urine retention, orthostasis, euphoria
Metaxalone	Unknown	Muscle pain due to spasticity	CNS depression, rash, GI disturbance, leukopenia, hemolytic anemia, hepatotoxicity
Methocarbamol	Unknown	Spasticity Tetanus	CNS depression, seizures, bradycardia, syncope, hypotension, rash, GI disturbance, leukopenia, vision changes, hypersensitivity reactions
Tizanidine	Reduced neuronal excitability via alpha-2 adrenergic agonist	Spasticity Chronic headache Migraine	CNS depression, hepatotoxicity, sweating, GI disturbance, dry mouth, constipation, urine retention

interventions must be carefully weighed, particularly for the palliative care patient who may have limited life expectancy.

Nursing care for spasticity focuses on comfort and maximizing function. Physical and occupational therapy consultation are invaluable for prescribed stretching regimens and to determine appropriate durable medical equipment. Patient and family education are important to set realistic goals. Education also focuses on factors that worsen spasticity, prevention of pressure ulcers and contractures, fatigue, and psychosocial concerns. Early education is crucial to prevent complications. Appropriate medication use and indications for their use are also taught. Repositioning, application of heat, and strategies to improve functional abilities are helpful.

Headaches

Case Study: A Patient with Migraine

Juana was 14 when she had her first migraine. Her migraine frequency gradually increased during her teen years. As a young woman, she missed 2–3 days of work per month as a result of her pain. After losing her job as a result, Juana went to see a neurologist. She had gained 80 pounds from a combination of inactivity and medication effects. With adjustments in her sleep, exercise routine, and medications Juana was able to return to full-time work.

Headaches are a common ailment—an estimated 78% of Americans will experience a tension-type headache in their lifetime and 16% will suffer a migraine.[23] Quality-of-life studies demonstrated that the impact of migraines on an individual is striking—in one study, 59% of migraine sufferers reported missing a family or social activity as a result of a migrainous event.[24]

A wide variety of conditions can trigger headaches and migraines. Common conditions encountered in the palliative setting include intracranial tumors, vascular disorders, infection, and head trauma. A selection of etiologies is found in Table 21.6. Of certain importance to the palliative care nurse is the medication overuse headache (MOH, also known as rebound headache), in which attempt at withdrawal from certain substances leads to onset of headache. The typical scenario encountered in MOH is a patient using acetaminophen, nonsteroidal anti-inflammatory drugs (NSAIDs), or combination migraine preparation. Other identified substances include caffeine, triptans, antidepressants, cocaine, estrogen, marijuana, and opioids.[25] The headache typically resolves in the absence of the offending substance after a period of days to weeks. In some cases, gradual reduction of dose may be a safer option, particularly if the substance has the potential for an acute withdrawal syndrome, as with opioids.

Migraines are not managed by pharmaceuticals alone. Lifestyle changes can change the frequency and intensity of migraine headaches. Nurses play a key role in patient education with many chronic and disabling conditions. Palliative care nurses are ideally situated to provide interventions aimed at improving patient self-management. Reducing or eliminating caffeine and tobacco use, adequate nutrition and hydration, weight reduction and exercise, appropriate sleep hygiene, and stress management are important. Education also focuses on appropriate medication use and avoidance of medication overuse.[26–28] A program in the United Kingdom documented the impact of a nurse-led intervention program focusing on these topics. At the completion of the study period, patients reported feelings of self-efficacy at headache management.[29]

Table 21.6 Causes of head pain

Headache syndromes	Cluster headache Tension-type headache Withdrawal/medication overuse headache
Migraine syndromes	Migraine with or without aura
Cranial and intracranial lesions	Metastatic brain tumors Primary brain tumors Skull base tumors Leptomeningeal metastases
General medical diseases and conditions	Fasting state/hunger Eyestrain Stress Muscle strain/tension, prolonged sitting, poor posture Sleep deprivation Stroke Vascular disorders Multiple sclerosis Increased intracranial pressure Sinus infection Temporal arteritis Varied infections, both systemic and CNS
Head trauma	
Atypical pain syndromes	Trigeminal neuralgia Postherpetic neuralgia

As with all neurologic changes in the palliative setting, the nurse begins with an assessment. The pain and its accompanying characteristics (intensity, location, quality, exacerbating/alleviating factors, response to previous therapies, related symptoms) can guide care. The typical tension-type headache is bilateral and characterized by a sensation of constant pressure. Episodic-type headache is thought to transform into tension-type headache with constant pericranial muscle tension. The pain can range from mild to moderate and, in extreme cases, can be severe. Conversely, migrainous events are commonly unilateral. The pain can be pulsatile in nature and is often associated with phonophobia, photophobia, and nausea/vomiting. Sleep alleviates the migraine and physical activity aggravates it. A significant number of migraineurs will experience an aura of transient sensory (usually visual), language, or motor disturbance. Focal deficits indicate either a complex migraine or, more seriously, a new intracranial lesion. The "thunderclap" headache of subarachnoid hemorrhage is a sudden-onset and very severe headache often accompanied by profuse vomiting and mental status changes. A headache accompanied by nuchal rigidity, vomiting, and photophobia suggests irritation of the meninges and warrants emergent evaluation. The typical headache of a patient with intracranial metastasis is dull, poorly localized, and of moderate intensity. Some patients will have ipsilateral pain to the metastatic lesion. Signs of increased intracranial pressure include an increase in pain intensity when lying down, coughing, or sneezing as well as nausea, vomiting, mental status changes, and pupillary changes. In some situations of headache, radiographic evaluation will be appropriate. Cerebrospinal fluid sampling via lumbar puncture may also be warranted.

Physical assessment includes palpation over the area of pain. Careful neurological examination may elicit deficits—skull base metastases will commonly compress an isolated cranial nerve. Leptomeningeal metastases will commonly result in multiple cranial or spinal neuropathies as well as headache.

Treatment is dictated by the classification of headache or migraine as well as by the etiology. The patient with an isolated skull base metastasis may find symptom stabilization and pain relief with palliative radiation or chemotherapy. Dexamethasone is commonly used in the palliative care setting because of its oral and parenteral formulations, lower mineralocorticoid effects, and ease of dosing.

Nursing interventions also include patient and family education. It is distressing to care for a loved one with severe, persistent headaches. Caregivers may express feelings of impotence to change the symptoms as well as loss and sadness in the setting of progressive neurologic deficits. Patients and family members benefit from education regarding pain management measures and medications. In the event of neurologic deficits, education about safety measures is important. Other nonpharmacologic interventions can be useful—ice and heat, reduced light/sound exposure, meditation and distraction, physical activity or rest, and positioning. Commonly, head-of-bed elevation is useful in the setting of increased intracranial pressure.

Impaired Communication

Case Study: A Patient with Speech Arrest Seizure

PJ was at his father's house when he had his first speech arrest seizure. He was found to have a brain tumor. Treatment stabilized the tumor, but PJ's speech was never the same—it was halting and difficult to understand. PJ's speech therapist made him a book for the bad days—he could flip through the laminated pages and find the picture for what he needed to communicate.

Communication is arguably at the heart of the human existence. Impaired communication is distressing to both the patient and his or her caregivers. Impairments in communication from neurological disorders can take the form of aphasia, mutism, deafness, agraphia, alexia, or dysarthria. Additionally, several conditions can impede the patient's ability to express wishes—the ventilator-dependent patient is one such example. The patient with a massive brainstem injury from a basilar artery occlusion is "locked-in" and has retained cognitive abilities but lost all control of his body save for voluntary eye movement.

Any number of disorders can result in impaired communication. Aphasia is caused by any disease disturbing the cortex of the brain responsible for language production or reception. Traditional neurologic teaching identifies the key cortical areas as Broca's area, Wernicke's area, and the supplemental motor area. Functional hemisphere dominance determines the localization of language in the right or left cerebral hemisphere. For most people, language production and comprehension occur in the left hemisphere.

Nursing care for the patient with disorders of speech or language focuses on strategizing alternative means of communication and maximizing functional ability for speech. As the case study illustrates, impaired communication is highly distressing and frustrating for patients and caregivers alike. If the patient is capable of cognition, the nurse identifies alternative communication strategies regardless of the patient's prognosis and the setting of care. Intensive care nurses and home hospice nurses alike can use communication boards, yes/no questions, and written instructions. Several key points are important for the patient with aphasia (Box 21.3).

Box 21.3 Key Points for Optimizing Communication

- Provide the optimal setting for communication: Ensure the patient has glasses on and hearing aids in if appropriate, adequate lighting.
- Avoid correcting grammatical mistakes or speaking for the patient.
- Do not raise the volume of your voice unless the patient is hearing impaired.
- Use facial expression to emphasize spoken communication.
- Face the patient directly while communicating.
- If the patient has other neurologic impairment such as a visual field cut, compensate by standing on the patient's best side.
- Simplify the message.
- Allow adequate time for cognitive processing and response.

Speech-language pathology consultation can be immensely helpful to clarify the specific communication deficiencies. Speech pathologists are a wonderful resource to the palliative care nurse for strategizing alternative communication methods. One particularly fascinating communication strategy for the patient with expressive aphasia is to use song rather than spoken word to communicate. Patients with nonfluent aphasia may be able to put words to a familiar melody in order to communicate. A technique known as *melodic intonation therapy* has been developed for patient with left-hemisphere lesions to increase length of spoken phrases. Music therapy has a potential role as well for the patient with communication difficulty.

Neurologic Diseases

A number of neurologic diseases result in devastating symptom clusters and require increasingly complex nursing care. Many of these diseases are progressive neurologic degenerative disorders such as ALS, MS, and Parkinson's disease (PD). This section will address the palliative care needs of these patients.

Amyotrophic Lateral Sclerosis

ALS, also known as Lou Gehrig's disease, is a devastating progressive neurologic condition characterized by progressive muscle wasting from denervation (amyotrophy) with hyperreflexia. ALS is the most common of all motor neuron diseases. It results from the destruction of both upper and lower motor neurons. There are both familial and sporadic cases of ALS, with familial cases accounting for approximately 10–20% of total cases.[30] The mechanism of neuron destruction is a defect in the degradation of misfolded proteins. The resulting accumulation and clumping of nonfunctional proteins results in neuronal death. The end result of the disease process is paralysis and respiratory failure.

Case Study: A Patient with Amyotrophic Lateral Sclerosis

Fred enlisted in the Marines as a young man. During training exercises he noticed his feet would cramp up. Within a few weeks, he noticed that he couldn't grip his flip-flop shoes in the shower and would walk out of the shoes without meaning to. The physician on base sent Fred for a magnetic resonance imaging (MRI) study of his back, but the scan was normal. An electromyogram revealed a pattern of fibrillations and positive waves—Fred had ALS at the age of 19. "I joined the military—I'm not afraid of dying. I'm afraid of being disabled and not having control of my body."

Fred's story highlights the fears and psychological distress that underlies a diagnosis with a progressive and devastating neurologic disorder. Table 21.7 highlights the typical symptom clusters of ALS.

The treatment team is prepared to address a number of symptoms as well as the emotional impact of the disease. Goals-of-care discussions are important early in the disease trajectory. Median life expectancy is less than 5 years, although life expectancy is considerably shorter if the patient declines medically administered nutritional or respiratory support. Riluzole is the only therapy demonstrated to extend survival and time to tracheostomy.[31] Gastrointestinal distress and liver enzyme elevation can occur with riluzole treatment. Nursing interventions for the patient with ALS focus on the impact on quality of life (QOL), symptom palliation, and functional ability as well as EOL planning and support. Family and caregiver support is key as data strongly suggest a heavy caregiver burden with this disease.

The ALS patient requires an extensive team. Neurologists, pulmonologists, speech pathologists, physical and occupational therapists, nurses (see Table 21.8), and social workers will all play a role. Functional assessment and physical/occupational therapy needs are immediate; patients may require assistive devices at diagnosis. Therapy services have been shown to maintain endurance and strength, promote functional independence, and limit complications and pain.[32–34] Formal speech-language pathology and nutrition assessment is needed for swallowing evaluation and feeding strategies. The patient with ALS is at high risk for malnutrition from dysphagia,[35] depression, cognitive impairment, difficulty with self-feeding and meal preparation, hypermetabolism, anxiety, respiratory insufficiency, and fatigue with meals—some of these problems can be managed with speech pathology and dietary intervention. Early intervention to maximize nutrition and feeding is shown to extend survival and improve QOL.

Augmentative communication strategies will become key as paralysis progresses. Both low-tech strategies such as alphabet boards and high-tech solutions like speech-generating devices can be helpful. Sialorrhea is a common and uncomfortable symptom of ALS. Unilateral radiotherapy to the salivary or parotid gland and botulinum toxin injection are effective interventions.

Table 21.7 Symptoms common to the patient with amyotrophic lateral sclerosis

Bulbar-onset	Limb-onset
Dysphagia	Muscle weakness
Dysarthria	Hyperreflexia
Sialorrhea	Fasciculations

The terminal phase of ALS is characterized by significant challenges, and symptoms are best managed by a hospice team.[36–38] The dying phase of ALS is often marked by pain, psychological distress, episodes of choking and loss of respiratory capacity, diminishing communicative ability, and increasing physical dependency. Sadly, symptoms from disease progression are commonly inadequately controlled. A remarkable responsibility thus falls to the family and caregivers. Should the patient opt for long-term ventilatory support (LTVS) or noninvasive ventilation (NIV), the family and caregivers will require considerable teaching—from managing the tracheostomy wound to airway suctioning and maintaining equipment. Aggressive symptom control is clearly indicated. Palliative sedation may be useful in select patients with ALS choosing to avoid or discontinue invasive ventilation.[39,40] Palliative sedation and physician-assisted suicide remain a topic of exploration and debate.[41]

The wish to hasten death is expressed not uncommonly in patients with terminal illness. The palliative care nurse must be prepared for assessment, intervention, and thoughtful discussion of these issues. Suicidality and depression are associated with poorer QOL in patients with ALS.[42,43] Depression and hopelessness require urgent attention. Pseudobulbar affect (PBA, also been called emotional incontinence) is common in patients with ALS. It is characterized by uncontrolled expression of emotion that does not correlate to the underlying mood. Frequently, the emotion expressed is inappropriate to the situation. Importantly, PBA is not isolated to ALS. It has been described in other neurologic disorders—MS, traumatic brain injury, Alzheimer's disease, and PD. Coadministration of dextromethorphan 20 mg with quinidine 10 mg (the latter to slow the metabolism of the first) has been found effective at treating PBA. A combination pill was approved by the US Food and Drug Administration (FDA) in 2010 under the trade name Nuedexta.

Parkinson's Disease

Case Study: A Patient with Parkinson's Disease

Angie's mother and grandmother died of Parkinson's disease. Angie knew she had a risk of developing it, and, when she was 52, she saw a neurologist for hand tremors. Within a few months, she had lost 10 pounds from the constant muscle tremors. By 57, Angie walked slowly with a stooped posture. She fell on her way to the bus stop and fractured her hip. While in rehab after her hip surgery, Angie's physical therapist encouraged her to take up a dance class for people with movement disorders. "That class has given me back a little piece of my life. I am more confident when I walk now. Who knew that it would take falling to make me not so afraid of falling."

Parkinson's disease is the second most common neurological degenerative disorder. Related conditions include multiple system atrophy and progressive supranuclear palsy. The defining characteristics of PD are tremor, postural instability, bradykinesia, and rigidity of the extremities or trunk. It is important to distinguish PD from *parkinsonism*. Parkinsonism is an umbrella term indicating that the patient has symptoms of PD that may not originate from loss of dopaminergic neurons in the substantia nigra.

As with ALS, care for the patient with PD requires a team of healthcare providers. The palliative care nurse will be initially focused on maximizing functional ability and diminishing falls.

Table 21.8 Nursing management of amyotrophic lateral sclerosis

Airway and secretions	Interventions
Sialorrhea	◆ Excessive saliva in the oral cavity: ◆ Anticholinergics, use with care due to risk of mucous plugging, orthostasis, confusion, sedation ◆ Glycopyrrolate, amitriptyline, atropine, benztropine mesylate, trihexyphenidyl, hyoscyamine, transdermal scopolamine[35] ◆ Radiation to salivary gland[58] ◆ Botulinum toxin to parotid gland (Scott et al.)
Mucous pooling	◆ Suction ◆ Cough-assist device ◆ Guaifenesin ◆ Beta blockers
Airway	◆ Early discussion of goals of care and patient preferences: ◆ Noninvasive ventilation (NIV) such as positive-pressure ventilation with CPAP, BiPAP ◆ Tracheostomy with or without long-term mechanical ventilation (LTMV) ◆ Oxygen support ◆ Positioning
Communication impairment	◆ Speech-language pathologist evaluation ◆ Alphabet boards, picture board, yes/no board ◆ Electronic equipment if appropriate
Pseudobulbar affect (PBA)	◆ Not a mood disorder but a separate mood disorder may underlie the PBA: ◆ SSRIs ◆ TCAs ◆ Dextromethorphan/quinidine[49]
Falls, loss of mobility	◆ Early physical and occupational therapy referral ◆ Home nursing referral ◆ Durable medical equipment ◆ Assistive devices ◆ Stretching, range of motion ◆ Positioning, exercises ◆ Anticipating toileting needs ◆ Energy-sparing strategies
Spasticity, cramps, ALS-specific pain	◆ Pain is common in ALS: ◆ Opioids ◆ Nonopioids ◆ Balancing opioids with concerns for tenuous respiratory status and patient preferences
Mood disorder, anxiety	◆ Strategies for managing requests for euthanasia/assisted suicide ◆ Increased risk for suicide, suicidal ideation ◆ Treat underlying depression, anxiety
Nutrition	◆ Changes in food and liquid consistency ◆ Smaller, more frequent meals ◆ Ensuring solid foods are soft and moist ◆ Using straws, chin-tuck maneuver if appropriate ◆ Gastrostomy tube if consistent with patient's preferences
Cognitive changes	◆ Frontotemporal dementia, although an unusual presentation, can occur in ALS patients ◆ Managing dementia behaviors
Terminal phase of ALS	◆ Early discussion with patients and caregivers about when to refer to hospice ◆ Highly aggressive symptom management ◆ Palliative sedation has been explored for patients with ALS[46]

Medication education, home safety, physical and occupational therapy, and establishing a routine of exercise and rest are important goals of nursing care. Interestingly, dance therapy and Tai-Chi have been found to improve objective measures of gait and balance for PD.[44–47] As PD and the dopaminomimetic therapies can result in a degree of autonomic instability, the nurse will evaluate for hypotensive episodes and gastrointestinal dysmotility. The speech therapist also has a role in the evaluation of the patient with PD—dysphagia, impaired communication, drooling, and aspiration are common. Fluctuating energy expenditure, medication–food interactions, impaired gastrointestinal motility, and impaired fluid balance leaves patients with PD at risk of nutritional deficiencies.[48,49] The nutritionist has a role across the disease trajectory for the patient with PD. One key point for the nurse is the potential for diminished drug absorption when PD medications are taken with protein-rich meals.

Box 21.4 Medications Commonly Used for Movement Disorders in Parkinson's Disease

Levodopa and Levodopa-Modifying Drugs

- Levodopa (l-dopa), levodopa/carbidopa (LC), and levodopa/benserazide (LB)
- Mechanism of action: Levodopa is the metabolic precursor to dopamine, carbidopa and benserazide increase the availability of levodopa in the central nervous system
- Dosing schedule: to prevent the "on/off" effects of levodopa treatment in some patients, tightly follow the prescribed schedule
- Rationale: Increases survival and quality of life
- Adverse effects: Nausea and vomiting, psychosis, compulsive behaviors
- Bioavailability of LC and LB when taken with protein-rich meals is reduced

Catechol-O-Methyl Transferase Inhibitors (COMT Inhibitors)

- Mechanism of action: Decreases metabolism of l-dopa
- Increases the half-life of l-dopa, LC, and LB, simultaneously increasing efficacy of doses
- Available as entacapone and tolcapone
- Leads to longer "on" periods and shorter "off" periods
- Notably, does not decrease the dyskinesia effects of l-dopa

Monoamine Oxidase Inhibitors

- Dopamine metabolizer
- Can reduce the needed dose of l-dopa by 30–40%

Dopamine Agonists

- Often used for initial treatment
- Lower risk of causing dyskinesia
- Available in extended-release formulations
- Shortened "off" time compared with l-dopa
- Risk of compulsive behaviors such as gambling, hypersexual behavior, and eating disorders
- Available in oral formulations, continuous subcutaneous infusion or as a continuous duodenal infusion via portable minipump
- Apomorphine injection for sudden "off" periods

The psychosocial needs of the patient with PD and the family must be addressed. The nurse assesses for depression, anxiety, and caregiver distress. Grief, feelings of loss, and uncertainty of the future are common. Financial concerns and social isolation should also be addressed. A summary of available medical treatments can be found in Box 21.4. The medication regimens for PD can be complex, and doses are terrifically time-sensitive due to the rapid onset/offset of activity of most levodopa-containing medications. For a select group of patients, surgical intervention has a role. Currently available surgical interventions include deep brain stimulator placement and ablative surgical techniques such as thalamotomy and pallidotomy.

The terminal phase of PD is typically heralded by progressive loss of mobility, worsening dysphagia, and aspiration. Parkinson's-associated dementia can occur as well. The palliative care nurse will expand the goals of nursing intervention to include continence care, preserving patient preferences, managing medication effects, and patient/family education about symptoms at the end of life (Table 21.9).

Huntington's Disease

Case Study: A Patient with Huntington's Disease

No one spoke of Theresa's grandfather. He had died after years in a state-run facility as a middle-aged man. Theresa was in journalism school when she decided to write a project on his life and death. Theresa uncovered records indicating the hospital was a psychiatric facility. She was able to interview a retired nurse who had worked there over the years when her grandfather was hospitalized. Theresa discovered the uncomfortable truth that her grandfather died of Huntington's disease (HD). In her research on HD, Theresa discovered that it is an incurable and hereditable condition. Theresa documented her reaction to this news, her subsequent interview with a geneticist, and her diagnosis months later as a carrier of the mutation.

Table 21.9 Nursing care in Parkinson's disease

Fatigue, falls, loss of independence	◆ Referral for physical, occupational therapy ◆ Dance therapy ◆ Tai-Chi to improve balance ◆ Home modifications ◆ Home nursing evaluation ◆ Durable medical equipment ◆ Evaluate for hypotensive episodes
Communication and swallowing disorders	◆ Impaired facial expression ("masked face") further impairs functioning ◆ Assess for pseudobulbar affect (PBA) if expressed mood and affect are discongruent

HD is characterized by a classical triad—dementia, choreoathetosis, and autosomal dominant inheritance. It is a devastating disease with all-encompassing effects on the patient and family. Indeed, the family is often familiar with the disease—typically a family will have affected members across several generations. HD is caused by the accumulation of the huntingtin protein and the resulting destruction of many brain structures, particularly the cerebral cortex and basal ganglia. Repetition of the trinucleic acid CAG encodes for huntingtin on the short arm of chromosome 4. The disease is diagnosed when the number of repeats exceeds 35. Patients are typically diagnosed in the third through the fifth decades of life, although juvenile-onset HD is well established. In the case of Theresa, she was found to have 52 repeats of CAG. As her case illustrates, identification of the causative gene has allowed recent generations to make informed life decisions. There is also a psychological burden of knowing that one will die of a devastating neurological disease. The ideal setting for the HD patient is in a multidisciplinary clinic that includes nurses with palliative care training. Affected patients ultimately require care with all personal needs.

Palliative care nursing for the patient with HD ideally begins with early identification. There is currently no cure for HD. There are little data to guide specific interventions but multidisciplinary palliative care teams will likely augment the care provided by the neurologist team.[50] The most outwardly obvious symptom is the movement disorder. Notably, the chorea may not be bothersome to the patient and should be treated only if it is functionally impairing to the patient. Treating the chorea must be done carefully and ideally with the assistance of a skilled neurologist. Dopamine-blocking agents and dopamine-depleting agents are both used.

Psychiatric disorders in HD are common and highly disabling. The cognitive dysfunction is progressive, but the psychiatric symptoms are typically static. Cognitive dysfunction typically precedes the onset of motor symptoms and evolves into full dementia. In the case of Theresa, she opted for semiannual neurocognitive evaluation: “I don’t want to be surprised by my disease. I want to be proactive and move into a living situation that fits my needs.” The neurocognitive effects of HD are characterized by bradyphrenia, poor spatial memory, diminished working memory, impaired capacity for planning, poor judgment, and decreased mental flexibility. No agent has been found to be effective at delaying the cognitive decline of HD—ACH-ase inhibitors such as donepezil are ineffective. Rivastigmine was studied in a small open-label study with modest improvements in motor function and cognitive impairment but has yet to be replicated in a large phase III trial. Psychiatric disturbances range from emotional lability and behavior disorder to major mood disorder, suicidality, or homicidality. Psychiatric hospitalization may be necessary for careful titration of medications.

As HD progresses, end-stage symptoms emerge (Table 21.10). Chorea progresses until the patient is unable to be still for more than a few moments at a time. Eventually, chorea gives way to a hypokinetic, abulic state and then to a vegetative state. Muscles become rigid. Patients may experience tremor, bradykinesia, and dysphagia. Many patients will be placed in residential facilities by this stage. Nursing care involves safety assessment, positioning, and feeding assistance. Patients commonly suffer pain from falls,

Table 21.10 Symptomatic treatment of Huntington’s disease

Chorea	◆ Treat carefully and only if distressing to the patient/functionally impairing ◆ Haloperidol 2–10 mg/day ◆ Olanzapine has been found to reduce chorea, stabilize mood, and augment antidepressants; may also improve ambulation ◆ Tetrabenazine improves motor function/suppresses chorea; monitor closely for Parkinsonism, mood disorder, suicidality, sedation, akathisia
Parkinsonism of HD	◆ Treated with standard PD therapy ◆ Poor candidates for neurosurgical interventions ◆ Often characterized by rigidity in the terminal stages of disease
Bruxism	◆ Separate from the effects of neuroleptics ◆ Well-managed with botulinum toxin
Dystonia	◆ May be painful ◆ Functionally impairing ◆ No specific treatment has been evaluated in trials
Aggressive behavior, mood disorder	◆ Antidepressants ◆ Antipsychotics ◆ Propranolol ◆ Mood stabilizers ◆ Buspirone ◆ Suicidal and homicidal assessment
Sleep-wake cycle disruption	◆ Sleep-wake disturbance may exacerbate HD symptoms in cognitive and emotional domains of functioning. ◆ Although efficacy is not established, scheduled hypnotics are reported in the literature ◆ See recommendations for practical management of disordered sleep in HD[59] ◆ Interventions for sleep-wake cycle disturbances

injuries, and hyperkinetic movements. The palliative care nurse facilitates occupational and physical therapy referrals when necessary. Speech therapy and dietetic assistance are also commonly required. Food and drink consistency may be modified, and dietary modifications can slow the weight loss. One fascinating feature of HD is weight loss in the setting of preserved appetite.

Certainly the most difficult task is supporting the patient and family through the inevitable decline. Emotional support and evaluation for mood disorder will be ongoing tasks for the nurse. Family and caregiver education will focus on the disease process and the risk for potentially affected family members. Early discussions about EOL preferences are also important. Because of the financial burden of care, the nurse will also facilitate conversation about financial planning.

Multiple Sclerosis

Case Study: A Patient with Multiple Sclerosis

Jon was a respiratory therapist. He noticed his left hand was numb when he was tightening the connections on a ventilator. The numbness slowly improved over a few months. When his left foot went numb, Jon talked with his doctor. An MRI scan demonstrated multiple lesions of various ages in the periventricular white matter of Jon's brain, consistent with MS.

MS is a neuroimmunologic disease with widely varying clinical courses. MS is typically diagnosed in young to middle adulthood. It is more commonly found in people of northern European decent and those living farther from the Equator. Prevalence is estimated at 5 to 200 per 100,000 persons.

MS symptom clusters have been well described in the literature. Although no cure exists for MS at present, much can be done to alleviate the symptom burden. Cognitive dysfunction is seen in severe disease. Patients describe disabling fatigue, functional impairments, bowel and bladder dysfunction, and sexual dysfunction among others (Table 21.11).

Managing disability is at the heart of nursing interventions for the patient with MS. Mobility and activities of daily living typically decline as the disease progresses. Early and scheduled physical and occupational therapy assessments are wise. Home and workplace modifications can preserve the patient's functional independence. As with most incurable diseases, emotional support is frequently necessary. MS is traditionally a disease of young adults—it strikes at a time when the patient may be contemplating marriage and pregnancy. The risk for depression is high. Referral to the MS Society can be helpful for patients—both peer support and case management services are available.

Myasthenia Gravis

Myasthenia gravis (MG) is a life-threatening neuroimmunologic disease. The disease stems from the destruction of acetylcholine receptors at the neuromuscular junction. The common presentation is a patient with fluctuating weakness of the muscles, especially the muscles innervated by brainstem motor neurons. Weakness can be induced with repetitive movement and strength is restored

Table 21.11 Managing symptoms of multiple sclerosis

Fatigue	Neurostimulants Amantadine Regular exercise Planned rest breaks, energy-sparing techniques
Cognitive dysfunction	Neuropsychological assessment
Neurogenic bladder: urinary frequency, urgency, bladder spasticity, incomplete emptying	Urinary retention: ◆ Bethanechol ◆ Intermittent catheterization ◆ Monitor and treat high postvoid residual volumes to reduce risk of urinary tract infection Frequency and urgency: ◆ Propantheline, oxybutynin
Sexual dysfunction	Men: PDE-5 inhibitors
Pain	Pain assessment Traditional methods of pain control can be effective, especially neuroleptics, gabapentin, tricyclic antidepressants
Tremor	Severe postural tremor can respond to isoniazid with pyridoxine Carbamazepine, Clonazepam Limb weights of small poundage applied to the wrists
Neurogenic bowel	Prescribed bowel program of: ◆ Scheduled toileting (especially after eating or exercising) ◆ Stool softeners, laxatives, suppositories, enemas if needed ◆ Digital rectal stimulation if needed
Mood disorder	Aggressive management of depression Referral for neuropsychological testing

with rest. Strength is characteristically restored dramatically with anticholinesterase drugs.

Case Study: A Patient with Myasthenia Gravis

Maggie was a college freshman. One afternoon after coming home from class, she noticed her face felt funny and it was hard to smile. Her roommate thought she was just anxious because midterms were coming up. While standing at the sink to brush her teeth that night Maggie noticed her eyes "were at half-mast like someone who's drunk and can't stay awake." She sought care in the emergency room. By the time she was admitted to the ER 8 hours later, Maggie's speech was slurred and she was having difficulty keeping her head up. She was admitted to the intensive care unit for respiratory insufficiency. The respiratory therapist assisting with the set-up for intubation checked Maggie's forced vital capacity (FVC) and found it to be dramatically low. Before the night was over, Madeline was intubated and on mechanical ventilation for respiratory failure.

MG was once a fatal disease shortly after diagnosis. Discovery of anticholinesterase-inhibiting medications has allowed many patients with MG to pursue full lives. Although there is no cure for MG, many with MG enjoy a full life. Treatment is initiated with thymectomy—hyperplastic thymus tissue is found in 70% of newly diagnosed patients with MG.[51] Anticholinesterase medications and immunomodulation are the backbone of therapy. Symptom control focuses on managing and preventing acute MG crisis. During crisis, palliative management focuses on symptoms of dyspnea and anxiety. In the long-term care of patients with MG, careful discussions about intubation and the possibility of prolonged mechanical ventilation are warranted. Some patients will ultimately require tracheostomy.

Intracranial Lesions

Intracranial tumors encompass both primary and metastatic tumors and may involve cerebrospinal fluid, bony structures of the skull and skull base, dura, and cranial nerves. Cancers that commonly metastasize to the CNS are lung, melanoma, renal cell carcinoma, breast, and colorectal. The most common primary CNS tumors include meningioma, the gliomas, embryonal tumors such as medulloblastoma, and primary CNS lymphoma.[52] The palliative care goals will be different for the patient with widely metastatic cancer, newly diagnosed intracranial metastases but stable system disease, and the patient with primary CNS tumors. A thoughtful discussion with the oncologist can be immensely helpful for the nurse in any of these settings. Symptoms of intracranial lesions vary widely by location of tumor (Table 21.12). Notably, patients with intracranial lesions can be asymptomatic.

Symptoms from CNS tumors result from edema, infiltration of normal brain by tumors, and mass effect—displacement of normal brain structures. The concern in cases of large lesions or significant edema is for brain herniation. Herniation involves displacement of a piece of brain tissue under a rigid structure such as the foramen magnum, tentorium, or falx cerebri. There are six distinct herniation syndromes: uncal (transtentorial), central, cingulate (subfalcine), transcalvarial, upward cerebellar, and tonsillar (downward cerebellar). In the uncal herniation, the most common herniation syndrome, the medial temporal gyrus compresses the brainstem and nearby cranial nerves. This scenario is typically heralded by an ipsilateral third cranial nerve palsy (the pupil fails to constrict when stimulated with light and the eye deviates inferiorly and laterally). Treatment for the palliative care patient typically incorporates high-potency corticosteroids. Corticosteroids restore the blood–brain barrier by reducing the permeability of vascular endothelial cells and thus reducing intracranial pressure. Steroids can alleviate headache and pain from metastases. The nurse will also avoid hypotonic intravenous solutions (this includes all dextrose-containing IV solutions except D5 0.9% NS). In emergency and intensive care situations, hypertonic intravenous solutions such as mannitol and 3% saline are used. This intervention is for short-term situations only as the brain gradually increases osmolality. Controlled hyperventilation is also used in these scenarios, although it is typically reserved for aggressive last-ditch efforts. In scenarios where it is consistent with goals of care, neurosurgical intervention may be appropriate. For the patient with impending herniation, removal of a portion of the skull (craniectomy) and lobectomy may be performed. Some patients may benefit from removal of the lesion—this applies to patients with most primary CNS tumors and to some patients with metastatic disease.

Seizures are not uncommon with intracranial tumors. Typically, seizures from primary brain tumors are focal in onset and can have localizing significance. Seizures from all intracranial tumors are usually well-managed with AEDs. Seizures also tend to respond well to lesionectomy. Patients with seizures from primary CNS tumors will usually experience improved seizure control with tumor treatment. Patients with known intracranial tumors who have not experienced a seizure do not require prophylactic treatment with AEDs.[6]

Muscular Dystrophy

The muscular dystrophies (MDs) are a heterogeneous group of inherited progressive degenerative diseases of the muscles. The pattern of muscle involvement, presence or absence of mild mental retardation, age at symptom onset, degree of creatinine kinase (CK) elevation, rate of symptom progression, and presence or absence of cardiomyopathy can suggest the specific class of MD. There are many types of MDs, with Duchenne and Becker MDs being the most common.

Advances in molecular and genetic science and the discovery of the dystrophin protein in 1986 by Kunkel heralded a phenomenal scientific leap. Diagnostic techniques have rapidly evolved in recent decades to allow relatively inexpensive and rapid diagnosis. For potential family carriers of dystrophies, the ability to detect genetic carriers is not insignificant. The palliative care nurse will appreciate the gravity of such information for affected families.

MDs generally affect skeletal muscles. The most common variety is Duchenne MD (DMD). This disease follows an X-linked pattern of inheritance and thus affects primarily boys. These children will commonly present before the age of 3 years with a rapid and progressing course of muscle weakness. Typically, the child will develop difficulty walking, standing, and stair-climbing first. This represents the initial involvement of the gluteal, quadriceps, and iliopsoas muscles. The walking difficulties will advance with the involvement of the pretibial muscles (as evidenced by foot drops and toe-walking). Eventually, shoulder girdle muscles weaken and the scapulae become winged. Eventually, the individual can be expected to develop spinal deformity such as kyphoscoliosis. Most

Table 21.12 Symptoms of intracranial lesion by location

Structure	Normal function	Altered function in the presence of tumor
Frontal lobe	Personality Voluntary skeletal movements Fine repetitive motor movements Eye movements	Personality change or disinhibition Altered responses to stimuli, emotional lability Difficulty with speaking, chewing, or facial expressions Uncoordinated swallowing, or movement of hands, arms, torso, pelvis, legs, and feet
Parietal lobe	Sensory processing: tactile, visual, gustatory, olfactory, auditory, body position	Trouble integrating language, vision and tactile stimuli Loss of sense of body positioning or vibratory sense Difficulty with verbal and nonverbal memory Paresthesias Loss of tactile discrimination Inability to write or do math calculations
Occipital lobe	Interpretation of visual input	Difficulty naming visual images and words Difficulty reading and writing, identifying colors Inability to identify if an object is moving
Temporal lobe	Auditory perception and interpretation	Right lobe: Difficulty hearing, understanding, organizing, and concentrating on what is seen or heard Inability to recognize musical tones and nonspeech information like illustrations Olfactory or gustatory hallucinations Vertigo, unsteadiness, or tinnitus Left lobe: Difficulty hearing, understanding, organizing, and concentrating on what is seen or heard Inability to recognize spoken words Vertigo, unsteadiness, or tinnitus
Cerebellum	Processing of sensory information from eyes, ears, and tactile and musculoskeletal receptors Refining motor activity into coordinated movement	Frequent loss of balance, unstable posture or gait Uncoordinated movement of extremities Alterations of some reflexive movements Nystagmus, muscle tremors, or ataxia
Brainstem and cranial nerves (CN)	*Brainstem:* gateway from cerebrum and cerebellum to spinal cord. Maintains consciousness, cardiovascular and respiratory functioning Relays motor and sensory information *Cranial nerves:* Nuclei of cranial nerves III-XII arise within the brainstem structures	CN I: loss of smell (anosmia) CN II: vision compromise, visual field defect CN III: loss of pupillary constriction and ability to raise eyelid, extraocular movements, diplopia CN IV: loss of inferior/medial eye movement CN V: inability to clench jaw and chew, numbness of mouth and nose, numbness of face, loss of corneal reflex CN VI: inability to abduct the eye CN VII: facial paralysis, taste disturbance, salivary and lacrimal dysfunction CN VIII: loss of hearing, disequilibrium CN IX: swallowing difficulty, taste disturbance CN X: loss of ear sensation, GI disturbance, voice hoarseness CN XI: difficulty turning head and shrugging shoulders CN XII: difficulty swallowing and articulating lingual sounds

boys with DMD are wheelchair bound by their second decade of life. These patients will most commonly develop respiratory insufficiency, pulmonary infections, and heart failure. Survival into the 20s and 30s was historically unheard-of.

In DMD, the normal dystrophin protein is not found in muscle cells. This leads to a loss of dystrophin-associated proteins and dystrophin-associated glycoproteins. These molecules are necessary for maintenance and function of the sarcolemma (the cell membrane of striated muscle cells). Without these proteins and glycoproteins, extracellular calcium and fluid flood the cell, leading to cell dysfunction and death. As muscle damage progresses, respiratory failure becomes evident. The initial clinical evidence of respiratory failure may be sleep apnea and/or weight loss as work of breathing increases. Ongoing discussions with the patient and family are clearly important with regard to patient wishes for assistive ventilation, electrophysiologic intervention, and resuscitation. Early screening (starting at age 10) and intervention at the first sign of an arrhythmia both in patients with DMD and carriers of DMD is considered the standard of care.

Treatment for DMD is limited and was historically aimed at slowing the disease. The management was limited to corticosteroids in an attempt to mitigate the inflammatory responses to intracellular myocyte damage. With advances in cardiac and respiratory care, some individuals are now living into their fourth and fifth decades. In recent years, pharmacotherapy advancements have led to FDA approval of a novel corticosteroid compound with indication of use in DMD.[53] Recent drug development targeting specific exons of the dystrophin gene have resulted in the first therapy (eteplirsen, marketed as Exondys 51) aimed at increasing skeletal muscle dystrophin levels.[54]

The role of the palliative care nurse for patients with DMD will evolve in coming years as treatments advance. Several disease-specific difficulties are currently common.[55] Patients with MD may struggle with constipation from immobility and poor abdominal muscle tone. Weight gain and osteoporosis can also be problematic as a result of chronic steroid therapy. Dietary education and interventions may alleviate these to some degree. The palliative care nurse will continue to advocate for independence, access to rehabilitation and respiratory therapy services, appropriate exercise goals, periodic cardiac evaluation, safety in the patient's environment, and educational achievement (including special education services). As the patient grows, seating, wheelchair, bracing, and equipment needs will evolve and require reevaluation with appropriate physical and occupational therapists. The palliative care nurse will remain attuned to the life-limiting nature of MD as well as to the potential impact on childbearing choices as patients reach adulthood. There is limited research available to the palliative care nurse on specific psychosocial needs of patients with MD. However, social integration and family caregiving needs are clear areas of needed support.[56,57]

Conclusion

Arguably, the role of the palliative care nurse is first to alleviate suffering and second to advocate for the patient's choices. The task of assisting the patient to identify his or her healthcare choices in the face of a devastating and often terminal neurological illness is no easy one. Box 21.5 lists additional resources to assist the nurse, patient, and caregivers. Several other themes emerge—advocating for early therapy referral, pain control, bowel and bladder care, preserving functional abilities, maintaining patients' independence, and providing education about medications and disease processes.

Box 21.5 Additional Resources

Seizures

Care of Adults and Children with Seizures and Epilepsy. 2nd ed. American Association of Neuroscience Nurses Clinical Practice Guideline Series. 2007. http://aann.org/publications/clinical-practice-guidelines.

Brain Tumors

van Breemen M, Wilms EB, Vecht CJ. Epilepsy in patients with brain tumors: epidemiology, mechanisms, and management. *Lancet Neurol* 2007;6(5):421–430.

Spasticity

NINDS Spasticity Information Page
http://www.ninds.nih.gov/disorders/spasticity/spasticity.htm
NINDS Motor Neuron Fact Sheet
http://www.ninds.nih.gov/disorders/motor_neuron_diseases/detail_motor_neuron_diseases.htm

Headache and Migraine

Canadian Headache Society Guidelines
https://headachesociety.ca/guidelines/
International Headache Society. Headache Classifications. 2nd ed.
http://www.ihs-headache.org/upload/ct_clas/ihc_II_main_no_print.pdf.

Aphasia

American Speech-Language-Hearing Association
http://www.asha.org/public/speech/disorders/aphasia.htm
National Aphasia Association
https://www.aphasia.org/aphasia-definitions/
Aphasia Hope Foundation
http://www.aphasiahope.org/
Academy of Neurologic Communication Disorders Science
http://www.ancds.org/

Amyotrophic Lateral Sclerosis

ALS Foundation Guide to Nursing Care for Patients with ALS
http://www.alsa.org/als-care/resources/publications-videos/factsheets/nursing-management-in-als.html

Parkinson's Disease

Johnson ML. Parkinson's disease: speech and swallowing. National Parkinson Foundation.
http://www3.parkinson.org/site/DocServer/Speech___Swallowing.pdf?docID=193&JServSessionIdr004=2u6sv9pks2.app337a.
National Parkinson Foundation
www.parkinson.org

Intracranial Lesions

AANN Guide to Care of the Patient After Craniotomy. American Association of Neuroscience Nurses Clinical Practice Guideline Series. 2007.
http://aann.org/publications/clinical-practice-guidelines

Muscular Dystrophy

Muscular Dystrophy Association, Duchenne Muscular Dystrophy Medical Management Guide, https://www.mda.org/disease/duchenne-muscular-dystrophy/medical-management

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CHAPTER 22

Anxiety and Depression

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Key Points

- Emotional distress in the context of palliative care is ubiquitous and multifactorial.
- Palliative care clinicians need to be attuned to patients' distress and the possibility of clinically significant depression or anxiety.
- Anxiety and depression are common but often underrecognized and untreated.
- Accurate screening and differential diagnosis are prerequisite for appropriate intervention, which may include various treatment modalities.
- Up-to-date education of patients and their families enhances their ability to successfully participate in their care.

Introduction

Anxiety and depression are terms that have penetrated our daily life vocabulary and have been used in clinical settings for identifying both symptoms and specific disorders marked by clinically significant anxiety and/or depressive symptoms. Depression has been shown to have negative consequences on both the patient and family, with data indicating a role of this clinical condition in reducing adherence to treatments, in increasing subjective perception of physical symptoms, and, possibly, in worsening prognosis.[1] Depression is also a major risk factor for suicide and desire for hastened death.[2] Palliative care nurses are uniquely positioned to confront the complex range of medical and psychosocial challenges faced by their patients. Psychological distress can affect patients' abilities to experience joy during their final days. It can amplify physical pain and impair their ability to do the emotional work of advance care planning or saying good-bye to family and friends.[3]

Prevalence

The National Consensus Project for Quality Palliative Care identifies psychological and psychiatric aspects of care as one of its domains and provides guidelines to the interdisciplinary team to assess and address psychological and psychiatric components of care based on the best available evidence to maximize patient and family coping and quality of life (QOL).[4] Table 22.1 introduces data on the prevalence of depression and anxiety in palliative care patients in various settings of care.

Patients with advanced disease often experience psychological problems as their physical symptoms worsen and previously mentally healthy individuals can become psychologically vulnerable as their disease progresses. In a study by Austin, 20% of palliative care patients showed clinically meaningful anxiety and depression as measured by the Hospital Anxiety Depression Scale (HADS). Younger age and lower Karnofsky Performance Status Scale scores were associated with higher HADS total scores.[5] In a study of patients with terminal cancer, mixed anxiety and depressive symptoms were the most prevalent subtype (16%), whereas 14.9% reported only elevated anxiety symptoms and 13.4% reported only elevated depressive symptoms on a HADS screening instrument. Anxiety was significantly positively correlated with other measures of psychological distress including depression, hopelessness, and desire for hastened death, and negatively correlated with social support. Women reported significantly higher levels of anxiety than men.[6]

A meta-analysis of mood disorders in long-term cancer survivors by Mitchell revealed a pooled prevalence of syndromal (clinical) depression to be 16.5%, prevalence of adjustment disorder 15.4%, and anxiety disorders 9.8%. They noted no association between mean age or sex and prevalence of depression or anxiety. Individual studies in this meta-analysis noted that predictors of depression or adjustment disorder included low performance status, high burden of symptoms such as pain and fatigue, previous depression, and low levels of support.[7]

Interestingly, a study by Hayes found the prevalence of depression to be higher in men compared to women (25.7% vs. 12.8%, respectively) and the odds ratio (2.3) was not reduced after controlling for stage of illness, time until death, delay in diagnosis, level of social support, diagnosis, age, and ethnicity. Among those who did need help with basic tasks, there was a strong association between gender and depression, with 37.8% of men who were dependent on others being depressed compared to only 2.4% of similarly affected women.[8]

Considerations in Non-Cancer Patients

Symptom burden in end-stage chronic obstructive pulmonary disease (COPD) is often equivalent to or worse than in cancers, as well as the end stages of other chronic diseases such as dementia, congestive heart failure, renal failure, and liver failure.[9] Although dyspnea is often the most prominent and debilitating symptom, patients with COPD also experience depression and anxiety. These are sometimes related to the functional and social consequences of dyspnea and may decrease QOL independent of disease severity.[10] In addition, depression is an independent risk factor for mortality, hospital readmission, and longer hospital stay.[11]

Table 22.1 Prevalence of depression and anxiety in palliative care patients

Study (Reference number)	Population	N	Interview	Prevalence
6	Stage IV cancer patients	193	HADS (cutoff 8)	13.4% only depression 14.9% only anxiety 16% mixed anxiety and depression
5	Mixed cancer, HIV/AIDS, and chronic pulmonary disease. Comparison between home-based and inpatients	92 (46 home-based and 46 inpatients)	HADS (cutoff 8) HADS H ≥19	Anxiety: 35% home-based 50% inpatients Depression: 37% home-based 53% inpatients 22% home-based 35% inpatients
7	Meta-analysis of 24 studies of mood disorders in palliative care settings	4007	Psychiatric interviews (e.g., structured, semi-structured or clinical interview)	16.5% syndromal (clinical) depression 15.4% adjustment disorder 9.8% anxiety disorders
8	Mixed home care and inpatient palliative service.	300	PRIME-MD	Depression: 25.7% men 12.8% women
23	Community palliative care patients with advanced progressive disease.	50	MINI	Major depressive disorder: 20%

HADS, Hospital Anxiety Depression Scale; PRIME-MD, Primary Care Evaluation for Mental Disorders; MINI, Mini International Neuropsychiatric Interview.

In a study of outpatients with symptomatic heart failure, the most commonly endorsed symptoms on the Edmonton Symptom Assessment Scale (ESAS) were anxiety (45%) and depression (43%).[12] Depression is one of the most common psychological symptoms seen in heart failure. Patients with heart failure and depression are at greater risk for multiple all-cause admissions and rehospitalizations and overall morbidity and mortality. When depression is comorbid with anxiety, the risk of mortality is even higher. Depressive symptoms are also associated with worse health-related QOL (HRQOL) in patients with heart failure, especially when depression is persistent.[13]

In a study of patients hospitalized with heart failure who were administered the HADS questionnaire, 41% of patients were identified with anxiety, 59% with depression, and 33% with both anxiety and depression. Female gender and poor social support were found to be associated with higher rates of depression and anxiety.[14] A meta-analysis of 23 studies including more than 10,000 participants with heart failure demonstrated that the prevalence of major depressive disorder was 20% in outpatients and inpatients. The prevalence of depressive symptoms rose to 30% when self-reported questionnaires were used.[15]

A systematic review of 60 studies in end-stage renal disease (ESRD) dialysis patients showed mean prevalence of anxiety to be 38% and depression 27%.[16]

While it is useful to acknowledge the similarities between the palliative care needs of patients with cancer and chronic illnesses, particular differences are also evident.[17] Individuals with chronic illness often have a more prolonged illness trajectory than cancer patients and, for that reason, may have different palliative care needs. Chronic illness typically robs individuals of physical and psychological well-being, employment, hobbies, friends, and self-esteem from an earlier age than those with cancer. Thus, after decades of progressive deterioration in their health and functional ability, individuals with chronic illness often reach the terminal phase of their life without many of the physical and social resources available to other dying patients.[18]

Screening

A number of instruments have been studied regarding how to screen for depression and anxiety, with the Depression Cancer Consensus Group reporting validity studies involving at least 19 tools designed to help clinicians identify depression in the cancer setting.[19] The American Society of Clinical Oncology's guidelines recommend that all patients with cancer and cancer survivors be evaluated for symptoms of depression and anxiety at periodic times across the trajectory of care. Assessment should be performed using validated measures, such as the Patient Health Questionnaire (PHQ-9) and the Generalized Anxiety Disorder (GAD-7) for screening of depression and anxiety, respectively.[20] If moderate or severe symptomatology is detected through screening, individuals should have further diagnostic assessment to identify the nature and extent of the symptoms and the presence or absence of a mood or an anxiety disorder.[20]

There is no consensus on how to best screen for depression in patients receiving palliative care. Low completion rate due to patient frailty, refusal, or cognitive impairment is not uncommon. Shorter screening tools may be easier to use for both patients and providers. The sensitivity and specificity of different screening tools for depression in palliative care range from 0.72 to 1.0 and 0.50 to 1.0, respectively.[21]

In a study by Chochinov involving palliative care inpatients, sensitivity and specificity of a single question, "Have you felt depressed most of the day, nearly every day for two or more weeks?" was 1.0 and therefore diagnostic of depression.[22] In a small study within community palliative care patients, the same single question had a high specificity of 0.85 and low false-negative value of 0.94.[23] Thus, this single question seemed most helpful at screening out those patients who are not depressed and therefore do not need more in-depth assessment of their mood. Due to low positive predictive value (0.57) in this study, it was determined that patients identified as possibly depressed by the single question need further assessment of their mood before they are started on treatment.

As far as screening for anxiety, the State-Trait Anxiety Inventory (STAI), the GAD-7, and the Fear of Disease Progression Scale have been reported as tools to be applied in cancer settings, although their acceptability is reported to be modest. The HADS is a suitable tool for initial screening for both anxiety and depression but it cannot be proposed as a diagnostic instrument. [24]

Diagnosis

Despite the fact that depressive and anxiety symptoms are common in patients receiving palliative care, these disorders are often misunderstood, underdiagnosed, and, hence, untreated. Studies indicate that up to 50–60% of depression in cancer patients is not properly recognized.[1]

There can be many barriers interfering with the recognition of clinically significant depression or anxiety. These may include:

- The clinician's own lack of knowledge or skill to diagnose and treat depression or anxiety
- Reluctance to bring up potentially upsetting topics (a very low proportion of patients discuss their low mood with their doctors or oncologists and choose to address somatic rather than affective and emotional symptoms)[25]
- Belief that depression is "normal" at the end of life
- Concerns about possible drug–drug interactions with antidepressants

Table 22.2 Psychiatric disorders with depression as a predominant symptom

Adjustment disorder with depressed mood	Significant depressive symptoms in response to a life stressor causing undue distress and interference with daily functioning.
Major depressive disorder	Depression or anhedonia lasting for 2 weeks or more and present for most of the time. Associated symptoms include: weight loss, insomnia vs. hypersomnia, psychomotor agitation or retardation, fatigue, feelings of worthlessness or inappropriate guilt, difficulty concentrating and suicidal ideation.
Dysthymia	Depressed mood is present for most of the time for at least 2 years. Additional symptoms include changes in appetite and weight, fatigue, poor concentration, feelings of low self-esteem and hopelessness.

Table 22.3 Psychiatric disorders with anxiety as a predominant symptom

Generalized anxiety disorder (GAD)	Pervasive and excessive anxiety about a number of events/activities, occurring more days than not for at least 6 months. Additional symptoms include restlessness, easy fatigue, difficulty concentrating, irritability, muscle tension, and sleep disturbance.
Panic disorder	Recurrent unexpected panic attacks
Adjustment disorder with anxiety	Occurs within 3 months of a major stressor and causes significant distress and functional impairments.
Phobias	Significant fear brought about by specific situations or objects (e.g., closed spaces, blood draws, needles). Often accompanied by avoidance of a feared stimulus.
Posttraumatic stress disorder (PTSD)	Follows a traumatic event. Presents with intrusion symptoms (e.g., memories), avoidance of stimuli associated with trauma and negative alterations in cognition and mood. Increased arousal and reactivity are also present.

The most widely used criteria to diagnose depression are those outlined in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5, 2013). If patients don't meet the full criteria for major depression or primary anxiety disorder, they can be classified as "adjustment disorder" with depressive and/or anxiety features. A proposal to adopt a "substitutive" approach to diagnosis of depression has been debated for years. It suggests replacing somatic criteria (e.g., poor appetite, fatigue, impaired sleep) thought attributable to medical illness or its treatment with other substitutes, such as depressed appearance, social withdrawal, brooding/self-pity/pessimism, and lack of reactivity in situations that would normally be pleasurable.[26]

However, most experts agree that, for clinical purposes, the use of an inclusive set of diagnostic criteria that incorporates both neuro-vegetative (somatic) and psychological symptoms of depression and emphasizes the presence of hopelessness, worthlessness, guilt, and suicidal ideation is most appropriate for the palliative care population.[27]

For the purpose of this chapter, we will focus on major diagnostic categories for both depressive and anxiety disorders that are most likely to be encountered in a palliative care patient population (see Tables 22.2. and 22.3). A reader interested in more detailed diagnostic criteria is recommended to turn to two commonly used systems in nosology, the DSM-5 (2013) and the International Classification of Diseases (ICD-10) for further information.

Depressive Disorders

Depressive syndromes are a common mental health problem in the palliative setting but they are often unrecognized and undertreated. Clinicians often fail to appreciate the extent of a patient's depression until too late in the course of the disease.[28] Depressed mood, sadness, grief, and anticipatory feelings of loss are all appropriate responses to advanced disease and dying. However, feelings of hopelessness, helplessness, worthlessness, excessive guilt, lack of pleasure, and suicidal ideation (even passive) are among the best indicators of depressive syndromes in these patients.[29,30]

On the other hand, feelings of hopelessness, helplessness, and guilt must be considered in the context of the patient's illness. Hopelessness may be difficult to interpret in the setting of a disease where there is no hope for cure or recovery.[31] Almost all patients with advanced illness experience a certain degree of disengagement from areas of interest. However, a pervasive anhedonia that extends to loss of interest and pleasure in almost all activities warrants attention as an important indicator of clinically significant depression. Symptoms that seem out of proportion to the patient's actual situation should prompt concern for major depressive disorder. Major depression affects approximately 7% of the general population (8–9% of female and 3–4% of men), with data in oncology indicating a prevalence between 15–40%, depending on several factors (e.g., type, stage of cancer, in/outpatient, on/off treatment, type of diagnostic tool used).[32]

Differential Diagnosis

Depressive symptoms caused by medications or underlying medical conditions need to be taken into consideration. The following list is certainly not exhaustive and outlines only a few common examples:

- Medications: corticosteroids, benzodiazepines, hormonal agents, amphotericin B, opioids
- Chemotherapeutic agents: vincristine, vinblastine, procarbazine, asparaginase, tamoxifen, interferon, interleukin-2
- Medical disorders: electrolyte abnormalities, folate and/or vitamin B_{12} deficiencies, hypothyroidism, adrenal insufficiency[33]

Many of these medications or medical conditions can also cause delirium, which often presents in a hypoactive form.[34] Patients may look depressed, withdrawn, or apathetic, and one has to have a high level of suspicion to make this important distinction between clinical depression and hypoactive delirium.

Symptoms of depression should also be differentiated from normal grief reactions. During their end-of-life stage patients often go through a period of sadness or mourning while adjusting to loss and working through the existential issues that may arise. This "preparatory grief" process is considered to be adaptive and appropriate. However, when a patient's grief becomes severe and lasting and includes pathological signs or symptoms such as persistent social withdrawal, pervasive hopelessness, or thoughts of suicide, they may be clinically depressed.[35] This distinction has clinical relevance for treatment as support for grieving patients may be different from support needed by those who are clinically depressed.[36]

Another important concept to consider as separate from major depression is demoralization. Loss of meaning and hope can determine a sense of worthlessness of one's own life which is the hallmark of demoralization. A number of studies have shown that demoralization in cancer patients is related to confrontation with existential stressors that, throughout the illness, can impair their sense of mastery and competence.[24] While patients with major depression perceive the source of distress within themselves, have feelings of guilt and anhedonia, and feel lack of motivation, those with demoralization perceive the source of distress outside the self, do not feel guilty (but feel subjectively incompetent to cope), do not present with anhedonia, and their sense of motivation is generally intact.[37,38]

Anxiety Disorders

Anxiety can be a natural response to suffering, uncertainty, disability, disfigurement, and impending death. Although exact figures are not available, anxiety that rises to the level of a psychiatric disorder likely impacts less than 10% of patients in palliative care.

For example, in the Coping with Cancer study, 635 patients underwent a prospective evaluation to determine the presence of anxiety disorders using DSM-IV criteria.[39] The main results were that:

- An anxiety disorder was present in less than 8% of patients.
- Anxiety disorders were more common among certain subgroups, including women, physically impaired patients, and in younger patients.

Patients themselves may not identify as "anxious" and may prefer to use different terms, such as "concerned," "scared," or "worried."[40] Although it does not always reach a clinically significant level, it is important to recognize the presence of anxiety and its potential sources[41]:

- Anxiety as part of one of psychiatric disorders
- Component of pain, dyspnea, nausea, or cardiac arrhythmias
- Metabolic causes: Hyperthyroidism, hypoxia, hyperthermia, hypoglycemia, hypocalcemia
- Adverse drug effects: Psychostimulants, corticosteroids, some antidepressants
- Drug withdrawal: Alcohol, opiates, benzodiazepines, nicotine, cannabis
- Psychosocial and spiritual concerns: Family, finances, dying, spirituality

Treatment

Anxiety or depressive symptoms warrant treatment if they are causing significant distress or impacting the patient's QOL or functioning. Treatment should be individually tailored and take into consideration the patient's overall medical condition, prognosis, frailty, and ability to actively participate in treatment (e.g., psychotherapy).

One should always take care to relieve any uncontrolled symptoms, especially pain. All patients should have an appropriate medical evaluation to assess for possible medical contributors to the patient's mood.

Different modalities can be employed separately or in combination to treat anxiety or depressive symptoms. Although there is a lack of controlled trials to support the efficacy of combined therapy, most experts recommend an approach that combines supportive psychotherapy with patient and family education along with judicious use of antidepressant medication[2]:

- Pharmacotherapy
- Psychotherapy (see the psychotherapy section of this chapter)
- Integrative therapies (e.g., hypnotherapy, art therapy, aromatherapy, meditation, massage, relaxation, music therapy)
- Patient and family education

Pharmacotherapy

Newer antidepressants (e.g., selective serotonin reuptake inhibitors [SSRIs]and serotonin-norepinephrine reuptake inhibitors [SNRIs]) have a favorable side effect profile and are generally safe to use in older adults and the medically ill population. All antidepressants are started at low doses and require at least 4–6 weeks at a particular dose to show efficacy. Patients who are not told this when beginning treatment may stop the medication prematurely. The dose may need to be increased after this initial period.[33] Tables 22.4 and 22.5 provide a list of commonly used antidepressants and psychostimulants, respectively.

Psychostimulants have a faster onset of effect and are the preferred initial option for patients whose life expectancy is less than 2–4 months or for those who need more urgent treatment. They can be administered along with an antidepressant, benefiting from the activating effect of the stimulant within days

Table 22.4 Medications frequently used to treat depression in palliative care patients

Medication	Side effects to consider	Comments
Serotonin reuptake inhibitors (SSRIs)		
	GI disturbances (nausea, diarrhea) Sexual side effects (decreased libido, delayed orgasm) Increased anxiety or restlessness, especially early in treatment. Headache Insomnia/somnolence	Full benefit in 4–8 weeks
Fluoxetine		Usually administered in A.M. The longest acting SSRI agent, does not require gradual discontinuation.
Sertraline		Usually administered in A.M.
Citalopram/escitalopram		May be either activating or sedating. A.M. or P.M. administration is reasonable. QTc monitoring warranted for at risk patients.
Paroxetine		Shortest acting SSRI agent: gradual discontinuation is recommended, otherwise unpleasant discontinuations syndrome (flu-like symptoms occurring within 2–7 days of stopping an SSRI) symptoms may occur. Tends to be sedating and administered in the evening.
Serotonin-norepinephrine reuptake inhibitors (SNRIs)		
	Similar to side-effects of SSRI: GI disturbances Sexual side effects Dry-mouth, constipation, urinary retention Treatment-emergent hypertension	Often first-line agents for patients who have comorbidities such as pain, neuropathy, or stress incontinence.
Venlafaxine		Can be beneficial for treatment of vasomotor symptoms of menopause. Discontinuation syndrome common when stopped abruptly.
Duloxetine	Hepatotoxicity in patients with pre-existing liver disease	Approved for treatment of fibromyalgia as well. Discontinuation syndrome common when stopped abruptly.
Other antidepressants:		
Mirtazapine	Dry mouth, sedation, weight gain Limited sexual side effects	Sedating, appetite-stimulating, administered at night. Anti-nausea treatment in chemotherapy. Solu-tab formulation available. May be used to augment other antidepressants (e.g., add sedating or appetite-stimulating effect).
Bupropion	Insomnia, dry mouth, tremor	Indicated for treatment of depression but not effective for anxiety disorders. May be useful in fatigued or lethargic patients. Also indicated for smoking cessation. Safe in depressed cardiac patients.

Source: Reference 33.

* Adapted from Mehta R., Roth A.: Psychiatric Considerations in the Oncology Setting[33]

Table 22.5 Psychostimulants used to treat depression or augment antidepressant treatment

Medications	Side effects	Comments
Methylphenidate Dextroamphetamine	Anxiety, insomnia, tachycardia, mood instability. At higher doses: nightmares, insomnia, tics, paranoia.	Useful in depressed patients at the end of life to help improve their mood, wakefulness and energy more immediately. May potentiate the analgesic effect of opioid analgesics and counteract opioid-induced sedation.
Modafinil	Headache, anxiety, insomnia, hypertension, palpitations, dry mouth, diarrhea, nausea, anorexia.	Possibly safer for patients with a history of seizures or cardiac arrhythmia.

Source: Adapted from Reference 33.

and from the longer acting benefits of the antidepressant effects in 4–6 weeks.[33]

For patients with chronic anxiety or mixed anxiety and depressive symptoms, an antidepressant is often the treatment of choice (e.g., an SSRI). However, as mentioned earlier, antidepressants usually do not provide immediate relief and may take a few weeks to reach a full effect.

Adding a benzodiazepine agent may help "bridge" the patient until that time. Benzodiazepines are also helpful in the management of acute anxiety reactions. One of the most commonly prescribed benzodiazepines is alprazolam. However, it is also one of the shortest acting agents in this group of medications (along with oxazepam and triazolam), which makes them less suitable for treatment of anxiety as they remain effective for limited periods of time and are associated with a higher risk of rebound anxiety and withdrawal syndromes.

Lorazepam can be dosed more frequently and is useful not only for anxiety, but also to alleviate nausea and panic attacks. Patients with compromised hepatic functions may do better with lorazepam, oxazepam, or clonazepam given that these drugs are metabolized by conjugation (no oxidation) and have no active metabolites.

Regardless of the agent chosen, the lowest dose should be used with careful titration to the desired effect. Benzodiazepines should be tapered off if they are causing adverse effects, such as oversedation, delirium, falls, or cognitive impairment. As disease states progress, especially during the last 6 months of an illness, these adverse events are more likely and benzodiazepines may need to be avoided, cross-titrated to longer acting agents, or discontinued.[42,43] They should preferably be tapered off gradually, when practically and medically possible.

At a low dose, sedating antipsychotic medications, such as olanzapine and quetiapine, are effective in patients with severe anxiety that is not controlled with benzodiazepines or who cannot take benzodiazepines. They can also be useful for patients with respiratory complications as they do not cause the respiratory depression that benzodiazepines can. Patients who have difficulty falling asleep may also benefit from sedating medications in the antidepressant family, such as mirtazapine, amitriptyline, trazodone, or doxepin.[33]

Psychotherapy

Every patient must find ways to cope with the life-threatening illness, its treatment, and its impact on QOL and family functioning. From the initial diagnosis of the disease to the challenges of survivorship and uncertainty of a disease condition that might change for the worse, some degree of distress is inevitable. Often the disease and illness are not the only major stressors patients experience in palliative care. Patients may experience concurrent stressors such as serious illness in their partner or in another family member; economic problems including work, insurance, and housing; and low levels of social support. Symptoms of anxiety and depression in the context of a high-level threat such as disease progression or imminent death represent an appropriate response and can be distinguished from reactions indicative of poor coping and unstable emotional status.[44]

Psychotherapeutic interventions to reduce anxiety and depression symptoms are effective irrespective of whether the patient's responses are a normal reaction to his or her illness experiences versus a pathological reaction. The typical modalities for psychotherapeutic interventions are individual- and/or family-based depending on the patient's needs, functional status, and capacity. Psychotherapy for outpatients is sometimes augmented with referral to supportive group therapies where patients benefit from peer support and psychoeducation.[45]

Psychotherapeutic interventions for anxiety and depression in inpatient palliative care settings are typically highly focused and often undertaken to assist the interdisciplinary team with behavioral management and reducing psychosocial complications that could prolong hospitalization. The initial goal is to reduce symptoms to a manageable level rather than to "cure" the underlying causes or to address the full scope of the patient's psychological concerns. Instead, the patient and therapist work together to identify one or two priorities that can benefit from immediate attention.[27,46,47]

Particularly for frail patients, engaging in "talk therapy" may not be necessary as environmental modifications or other logistical interventions can be highly effective in reducing distress. These adjustments may involve providing the patient with more autonomy and control over decisions such as daily activities, timing of medication administration and nursing assessments, as well as food delivery schedules. Other examples of brief interventions that can substantially support the patient's coping include helping the patient communicate with the medical team to clarify understanding for informed decision-making or with family members to broach highly charged issues that require timely attention. All efforts undertaken to support the patient's coping and reduce distress should align and synergize with the overall goals of the interdisciplinary palliative care team.[47-49]

Regardless of whether the patient is referred for anxiety and depression management during the course of hospitalization or as an outpatient, some degree of assessment is necessary to clarify the presenting symptoms and their context. The initial assessment focuses on identifying the patient's primary biological, psychological, and social concerns and detailing the associated symptoms, duration, and situational factors that contribute to the difficulties that have been identified by the palliative care team.

Such descriptive information leads to diagnostic clarifications, including differentiation between normal responses to stressors that may improve with limited intervention versus meeting criteria for psychiatric conditions that warrant more intense treatment approaches.[50]

Patients with complex presenting problems require the clinical assessment to be comprehensive enough to pinpoint the underlying beliefs, conflicts, and dynamics driving the anxiety and depression symptoms that the patient outwardly expresses to the world. The assessment must also remain sufficiently focused on specific problems in order to formulate interventions that are targeted and relevant to the patient's current health status.[50]

Key considerations in individual psychotherapy in the palliative care setting are the development of a strong therapeutic alliance with the patient and the establishment of trust to normalize the symptoms, fears, and concerns that characterize the illness experience and to provide coping strategies for dealing with negative emotions and the crisis at hand. Techniques to facilitate adaptation help patients use more effective coping strategies and are typically embedded in one of several theoretical frameworks of psychotherapeutic interventions. These frameworks provide a roadmap to guide assessment and interventions, and most therapists blend elements from different approaches and tailor their treatment according to each client's needs.

Psychotherapeutic treatment in palliative care is typically short-term with a duration ranging from a single session to multiple visits across several weeks focused toward goals that are relevant and feasible to achieve. A common approach in brief psychotherapy is to help the patient identify what is out of their control and what can be changed. For the latter, an active, problem-focused coping approach can be most helpful. In cases where the stressor cannot be changed, such as the need to cease employment due to illness, the therapist may guide the patient toward emotion-focused coping strategies such as cognitive reappraisal or acceptance.

Many of the interventions used in short-term psychotherapy in palliative care originate from the cognitive-behavioral therapy (CBT) framework. The fundamental premise in the cognitive behavioral framework is that psychological distress is connected to cognitive factors, including cognitive schemas, belief systems, cognitive distortions, and dysfunctional or maladaptive beliefs. Interventions are designed to target and alter these maladaptive cognitions or beliefs.

Patients are helped to understand and restructure their maladaptive cognitions and beliefs surrounding anxiety-provoking situations and to learn to develop a coping plan for distressing situations. Techniques used toward these goals include self-talk, relaxation training, worksheets for behavioral activation and cognitive restructuring, daily logs of thoughts, feelings and behaviors, and more.[51]

Other evidence-based interventions that are increasingly incorporated in palliative care are rooted in emerging psychotherapeutic frameworks such as acceptance and commitment therapy (ACT), and mindfulness. The main focus of ACT is to increase psychological flexibility by engaging in acceptance, cognitive diffusion, practicing being in the present moment, and identifying and working toward the individual's values and committing to actions.[52]

Mindfulness is the awareness that emerges through paying attention, purposefully and nonjudgmentally, to the unfolding of experience from moment to moment, including one's thoughts, feelings, and bodily sensations.

Therapists and patients work together to address problems with adjustment to illness. Challenges with adjustment are often characterized by anxiety about treatment or existential concerns and depressive symptoms, including decreased motivation and sadness. Some patients also exhibit beliefs and behaviors that interfere with adherence to their medical treatment, and these may need to be addressed collaboratively with the palliative treatment team.

Treatment may include providing resources and assessing the specific needs of the patient, such as the need for a new or updated assessment for psychotropic medication and referrals for pain management or assistance with lifestyle management to reduce disease-related risks (e.g., nutritional and physical activity counseling) and to other members of the palliative care team (spiritual care, etc.).[50]

Key considerations in family therapy for the palliative care patient are to help the family manage communication about the illness, particularly as it concerns balancing the amount of information given to the frail or disabled patient about his or her illness and ensuring that secrets about the disease are not kept. Therapists may work to help activate social support and assistance from family members to the patient, if not already provided, and to actively collaborate with the multidisciplinary team. Communication technology such as texting, sharing photos over the Internet, emailing, and using social media may reduce the sense of isolation experienced by both the hospitalized patient and the family remaining at home.

For some patients, therapists may encourage the primary caregiver to avoid isolation and find sources of support for themselves. Caregivers may also be encouraged to set new routines while continuing to meet the needs of others in the family. In this manner, the therapist attempts to encourage the family to not let the illness dominate their lives. For patients in a partnered/marital relationship, the stress of a chronic illness has the potential to take a toll, particularly if a marriage was fragile prior to the diagnosis. Financial pressures, time spent apart due to the hospitalizations, changing roles in the relationship, and disrupted family routines can result in a loss of closeness and intimacy as well as direct conflict. Referral to a marriage and family therapist in the community may be helpful.

Therapists can partner with caregivers to look for opportunities for patients to exert control and gain a sense of mastery in their environment. Opportunities for making decisions, voicing wishes, and exercising appropriate control can reduce feelings of hopelessness, bolster a sense of self-efficacy, and improve mood and adjustment. Helping family members learn how to support patients as they work to maintain a level of independence can also be extremely important for the patient and the caregivers.[53]

Integrative Therapies

Evidence-based interventions that have shown promise with patients with depression include integrative therapies such as a acupressure, breathing exercises, guided imagery, relaxation, and emotive imagery in management of symptoms of depression and anxiety in patients with cancer.[54] Massage therapy has also been shown to reduce patient–reported experience of pain, anxiety, and depression symptoms. A systematic review of the effects of massage therapy on the alleviation of pain, anxiety, and depression yielded some promising results. Patients with limited social support and limited experience with physical contact and affection benefited most from the massage experience.[55]

Patient and Family Education

Educated and empowered patients and families are better equipped and motivated to understand and manage their chronic illness. Effective patient education has been shown to improve adherence with patient instruction and reduce pain and anxiety.[56] Effective patient education is evidence-based and includes materials that reinforce understanding. In most facilities, nurses can partner with health educators who are skilled at developing patient-friendly, culturally sensitive, and health literacy–appropriate patient education. The goal of patient education is to increase patient/caregiver knowledge of health information and to assist patients who struggle to understand instructions. It seeks to engage, motivate, and empower patients with skills to self-manage their illness.[57]

Nursing's Role in Patient Education

Team-based care is becoming the paradigm in delivering complex care for patients with chronic disease.[58] Nurses are ideal for delivering psychoeducation to reduce symptoms of anxiety and depression in palliative care.[54] Educating patients and their caregivers is an integral part of nursing practice,[59] with nurses having the established rapport and inherent trust with patients to facilitate the transfer of crucial knowledge. The education should be systematic, sequential, and take into account the patient's/family's specific wishes and cultural, linguistic, and socioeconomic background.[59]

In palliative care, patient education should focus on empowering patients to self-manage anxiety and depression.[60] Nurse-delivered, evidence-based, psychoeducational interventions focusing on problem-solving, coping techniques, and management of depression symptoms improve outcomes among depressed palliative care patients.[61,62] In a 2017 study, patients who received palliative care with education and coping skill-building at the time of hematopoietic stem-cell transplant experienced "remarkable and sustained improvement" in depression and posttraumatic stress disorder (PTSD) symptoms 6 months posttransplant.[63]

Health Literacy

Patients face myriad challenges in understanding health messaging, including language and reading problems and a complex healthcare system. Nearly 9 out of 10 American adults have difficulty using everyday health information.[64] Margolis (2014) found that patients retained 50% of the health information they received, with half of it being recalled incorrectly.[65] Pain, illness, worry, medication, and lack of sleep can make it hard to process and remember health information.[66]

The impact of health literacy and patient empowerment on physical and mental health is significant. Lower health literacy is associated with worse physical health and depression and anxiety.[70]

The ability to understand and retain medical information depends on the clinician's communication style as well as the patient's education, language skills, motivation, cultural beliefs, and anxiety about the clinical encounter. The nurse must take precautions to assess the patient's readiness to receive information; to communicate that information in a calm, nonthreatening, and supportive manner; and to use plain language and limit medical jargon.[66]

Teach-Back

"Teach-back" is a simple intervention that improves provider communication and patient health outcomes.[56,68] It requires the patient who receives education to explain, in his or her own words, what he or she understands and needs to do. Research shows teach-back improves outcomes in cancer screening rates through provider communication training[68] and increases in glycemic control in diabetic patients.[69]

During patient education, the nurse should use teach-back frequently to ensure patient understanding. Listed here are some suggested techniques for utilizing this simple but powerful tool[67]:

- Use a caring tone of voice/attitude.
- Make eye contact and show relaxed body language.
- Use plain language.
- Ask the patient to explain back, using her own words.
- Ask nonshaming, open-ended questions.
- Avoid asking "yes" or "no" questions.
- Emphasize that the responsibility to explain clearly is on you.
- If the patient is not able to teach-back correctly, explain again and repeat teach-back.
- Use reader-/patient-friendly materials (print/images/video) to enhance learning.
- Document use of and patient response to teach-back.

Patient Empowerment and Self-Management

The Institute of Medicine defines self-management as "the systematic provision of education and supportive interventions to increase patient's skills/confidence in managing their health problems, including goal-setting and problem-solving support."[60] The Chronic Care Model posits that patients with chronic illness need education and support to become effective managers of their own health condition.[71]

Developing Self-Management Goals

To increase patient's self-management and self-efficacy skills, the nurse must provide:

- Easy-to-digest information
- Tools for building self-management and problem-solving skills
- Ongoing support from care team, friends, and family

The nurse and patient/caregiver should set achievable, patient-centered goals and create a follow-up plan:

- Nurse assesses patient's skill, understanding, and confidence in managing symptoms.
- Patient identifies an action plan with specific goals/behaviors.[60]
- Nurse creates structured follow-up to review goals/progress via clinic visit, phone, or email.

Follow-Up for Patients with Chronic Conditions

Structured follow-up is an essential part of chronic care and self-management development and reinforcement.[73] The following are helpful tips in planning follow-up calls with patients and families:

- Schedule follow-up based on mutual goals developed with patients and families. Be flexible in allowing patients to determine the follow-up method.
- Include problem-solving techniques to help patients identify problems and create solutions in follow-up.
- Don't skip follow-up.

- Follow-up can be by phone, email, fax, home visit, clinic visit, or other. If possible, use trained, culturally competent lay people for follow-up.

Web and Technology Solutions

Creative use of technology can help nurses connect with patients and provide effective, efficient patient education, self-management, and follow-up via web-based modalities/resources.[73] Telephone follow-ups and Internet-based interactive counseling/support have been shown effective in reducing depressive symptoms in cancer patients.[54] A recent systematic review of web-based CBT interventions found them to be effective for improving distress in physical illness, although evidence in cancer is still limited.[74]

Conclusion

Depression and anxiety are common in palliative care patients, but clinically significant symptoms are often unrecognized and untreated, which can add to patients' suffering and undermine their QOL. Active screening for depression and anxiety is recommended, and it should be combined with a systematic plan for appropriate intervention in order to be effective. Optimal treatment may involve the use of psychotropic medications, psychotherapy, and, in some cases, complementary treatment modalities. Patient and family education is indispensable in helping patients and their families to feel empowered by contributing to their care.

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CHAPTER 23

Delirium, Confusion, and Agitation

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Key Points

- This chapter examines the symptoms, causes, and management of delirium, with a special emphasis on nursing management and family interventions.
- Delirium can be difficult to recognize.
- Delirium is preventable in some circumstances and, when present, can be treated to relieve symptom burden.
- Delirium is a critical issue in palliative care and requires thoughtful diagnosis and skilled management.

Introduction

Delirium is an increasingly common complication of modern medical care. As we succeed in keeping sicker patients alive longer, they are more likely to develop the signs of global brain dysfunction called *delirium*. Delirium is characterized by disturbances in awareness, cognition, and attention. Attention is the ability to focus, shift, or sustain concentration. An electroencephalogram (EEG), though not usually clinically necessary, will confirm the global nature of the brain deficits in delirium and show generalized diffuse slowing. Onset is acute or subacute, and patients are confused and disoriented. Typically, the symptoms of delirium are most severe at night, when patients are more likely to be alone and when the orienting stimuli of the home or hospital routine are reduced. This pattern of diurnal variation is known as *sundowning*. Sundowning occurs because of this global brain impairment. It describes a symptom pattern, not a cause of delirium.

The *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition (DSM-5) defines five criteria for delirium: (1) deficits in attention and awareness, (2) symptom onset over a brief time period, change from baseline, and symptom fluctuation, (3) additional deficits in cognition (e.g., orientation, memory, perception), (4) not better explained by another neurocognitive disorder (e.g., dementia) or occurring in the context of severely decreased arousal (e.g., coma), and (5) the medical history, physical examination, or laboratory results indicate the delirium is a direct result of another medical condition(s) (e.g., disease, intoxication, or multiple etiologies).[1] The DSM also specifies subtypes based on duration and behavior.[1] Acute delirium lasts a few hours or days, while persistent delirium can last for weeks or months. Behavioral subtypes are hyperactive, hypoactive, and mixed delirium.[2,3] Patients with hyperactive delirium are more likely to become agitated. On the other hand, patients with hypoactive delirium are more likely to go undiagnosed and not receive treatment.[4] Delirious patients may become psychotic and develop hallucinations or delusional beliefs. Hallucinations in delirium are more commonly visual. Unlike the complex delusions sometimes seen in schizophrenia, delusions in delirious patients are usually vague and simple, like the belief that hospital staff are trying to kill the patient.

Epidemiology and Prognosis

The incidence of delirium varies from 40% to 80%.[5] In settings where more complex care is provided, such as the intensive care unit (ICU) and hospice settings, delirium is more common, affecting up to 80% of patients.[6] The mortality rate associated with delirium is 20%.[5] Dharmarajan et al.[7] hypothesized that the relationship between delirium and a series of hospital-acquired conditions such as falls, pressure ulcers, sleep deprivation, and aspiration likely explains the high mortality rate in this population. Persistent delirium is an ominous symptom associated with a very poor prognosis.[8,9] Terminal delirium is a label used to describe the persistent delirium which often occurs during the dying process.

Morbidity related to delirium includes cognitive decline,[10] extended hospital stay,[11–13] readmissions,[14] placement in long-term care facilities,[15,16] decreased quality of life,[3–4,17] caregiver burden,[4,17,18] and increased healthcare costs.[11] Management and treatment of delirium costs an estimated $164 billion per year.[15]

Medical noncompliance and other behavioral disturbances related to delirium can cause complications of their own.[3,19] A particularly troubling manifestation of severe delirium is agitation. When confused, agitated, or fearful, patients may remove catheters, physically hurt others, miss scheduled medications and procedures, wander, fall, and generally require intensive supervision.[3] Delirium contributes to cognitive decline, loss of independence, and mortality.[15] Yet delirium is not recognized about 60% of the time,[20] especially in its milder forms or when delirium is of the hypoactive type.[3,4,19] Oosterhouse et al. found ICU nurses frequently missed diagnosing delirium, especially in older patients or those experiencing hypoactive delirium.[3] Nurses did identify pertinent risk factors for delirium (sepsis, hypoxia, dehydration, sleep deprivation), but did not recognize the implications of these findings for altered mental status. Despite the existence of Clinical Practice Guidelines,[12] nurses demonstrated gaps in knowledge and problematic attitudes and beliefs about delirium. The study identified examples of coaching, team-based rounding, and utilization of care pathways with potential to improve nursing diagnosis of delirium.[3] Most delirium research has focused on acute care settings. Early interventions, both psychosocial and medical, have been shown to be effective in the management of this neurobehavioral syndrome, improving outcomes for patients and reducing stress for caregivers.[3,21]

Pathophysiology and Etiology

Delirium has been described as a combination of pathophysiology resulting from direct brain insults (e.g., hypoxia, infarcts, drugs) and/or abnormal stress responses (e.g., infection, postoperative metabolic dysregulation).[22] Although the precise mechanism of delirium remains unclear, there is general agreement that this syndrome involves aberrations in cholinergic, gamma-aminobutyric acid (GABA), and glutamate transmission; cerebral metabolism; the reticular activating system; and the inflammatory response.[22–25] Research to identify biomarkers for delirium is in an early stage.[20,26]

Hypoxia, infection, metabolic abnormalities, sleep deprivation, trauma, medications, drugs, and other derangements can cause or contribute to delirium. To help identify the multiple causes of delirium, the authors have found it helpful to use mnemonics. Two common mnemonics for the causes of delirium are "I WATCH DEATH"[27] and "DELIRIUMS"[28,29] (see Table 23.1).

Infection, a common cause of delirium, does not have to be severe to affect vulnerable brains. For example, in patients with dementia, even a mild urinary tract infection can cause delirium. Frequent pharmacological causes for delirium include anticholinergic medications (e.g., amitriptyline or cyclobenzaprine) and the over-the-counter antihistamine diphenhydramine. However, many other classes of medications like steroids, opioids, and sedatives can contribute to delirium. Metabolic and physiological factors such as dehydration, hyponatremia, and alcohol withdrawal can also produce delirium. Alcohol withdrawal can easily be missed when patients are not forthcoming about their alcohol history and families are unaware of the extent of alcohol use. When thinking about delirium, it is important to remember that delirium is usually multifactorial,[20] with between two and six possible causal factors.[30] A single causal factor can be identified in fewer than 50% of cases.[31]

Differential Diagnosis

Delirium can be distinguished from dementia on the basis of several factors. Delirium tends to be associated with acute onset rather than chronic progression and can sometimes be temporally associated with a disease process or a medication change. Although delirium and dementia are distinct disorders, they share the common substrate of a damaged brain. A brain damaged by dementia is much more likely to develop delirium.[10,15] A common clinical scenario is that of a patient with dementia who is pleasant and cooperative, but develops hypoxia. Here, delirium is superimposed on a preexisting dementia. Repeated

Table 23.1 Common mnemonics for the causes of delirium

***I WATCH DEATH* mnemonic**[27]		
I	Infection	Urinary tract infection, encephalitis, meningitis, pus, skin/soft tissue, pneumonia, Human Immunodeficiency Virus
W	Withdrawal	Alcohol, barbiturates, benzodiazepines, sedatives, illicit drugs
A	Acute metabolic disorder	Electrolyte imbalance, hepatic or renal failure, altered pH, hyper/hyponatremia, hyper/hypocalcemia
T	Trauma	Head injury, subdural hematoma
C	CNS pathology	Stroke, hemorrhage, tumor, ictal/postictal states
H	Hypoxia	Anemia, cardiac failure, pulmonary embolus
D	Deficiencies	Vitamin B_{12}, folic acid, thiamine, niacin
E	Endocrinopathies	Hypo/hyper thyroid, hypo/hyper glycemia, hypo/hyper cortisol
A	Acute vascular	Shock, septic hypotension, vasculitis, hypertensive encephalopathy
T	Toxins, substance use, medication	Alcohol, anesthetics, benzodiazepines, anticholinergics, narcotics, corticosteroids
H	Heavy metals	Arsenic, lead, mercury
***DELIRIUMS* mnemonic**[28,29]		
D	Drugs, dehydration, detoxification, deficiencies, discomfort (pain)	
E	Electrolytes, elimination of abnormalities, environment	
L	Lungs (hypoxia), liver (hepatic failure), lack of sleep, long emergency department stay	
I	Infection, iatrogenic events, infarction (cardiac, cerebral)	
R	Restraints, restricted movement/mobility, renal failure	
I	Injury, impaired sensory input (doesn't have glasses, hearing aids, dentures), intoxication	
U	Urinary tract infection, unfamiliar environment/people	
M	Metabolic abnormalities (glucose, thyroid, cortisol, poor nutritional status), metastasis (brain), medications (anesthetics, benzodiazepines, anticholinergics, narcotics, corticosteroids)	
S	Subdural hematoma	

episodes of delirium may worsen preexisting chronic brain disease like dementia, even after the delirium resolves.[15,16]

Delirium can also superficially resemble depression, particularly with hypoactive delirium. Delirious patients, in their confusion, can be quiet and withdrawn. They may also sleep poorly because of the sleep–wake cycle disturbances associated with delirium. A key feature distinguishing delirium from depression is disorientation.[32,33] Although depressed patients can perform poorly on cognitive tasks because of a lack of motivation and concentration, they are not disoriented and confused.

Sometimes delirium can be misdiagnosed as a primary psychotic disorder. Epidemiology is crucial here. For example, an 80-year-old person with no prior psychiatric illness does not suddenly develop schizophrenia. Also, patients with schizophrenia or bipolar disorder are not usually disoriented unless they are also delirious.

The term *catatonia*, which historically had been used to describe a subtype of schizophrenia, has now been defined more broadly. Features of catatonia can be seen in delirious patients. Catatonia is a psychomotor syndrome characterized by stupor, mutism, negativism, posturing, and stereotypical movements.[34] Catatonia can be associated with psychiatric disorders like schizophrenia or depression, but it can also occur in the kinds of metabolic derangements that cause delirium. Indeed, the two disorders can overlap. Because catatonia is relatively responsive to treatments like lorazepam, it is important to look for catatonic features in delirious patients. The Bush-Francis Catatonia Rating Scale, based on the DSM-5 diagnostic criteria, is a useful clinical screening tool for catatonia.[35]

Assessment

Delirium is usually first noticed when a patient acts confused, becomes agitated, or exhibits other worrisome behaviors. As symptoms of delirium may wax and wane, recognizing delirium sometimes requires ongoing assessment. The patient may appear vacant, abstracted, or emotionally labile. The regular use of delirium screening tools has been shown to improve early identification of this syndrome in complex care settings like ICU, geriatrics, oncology, and hospice.[12] Some instruments like the Confusion Assessment Method (CAM) screen for the diagnostic criteria of delirium,[36] while others, like the Memorial Delirium Assessment Scale, assess severity of symptoms.[37] Table 23.2 provides a limited

Table 23.2 Common screening or assessment measures for delirium and cognition

Test	Information	Time to admin
Presence of delirium		
Confusion Assessment Method[36] (various types)	Multiple versions ranging from 2–9 items Recommended in Clinical Practice Guidelines for Pain, Agitation, and Delirium (2013 – CAM–ICU) Recommended in the Geriatric Emergency Medicine Guidelines (2013 – Brief CAM) Requires training via manual Rater: clinicians	2–5 mins
Intensive Care Delirium Screening Checklist (ICDSC)[70]	Recommended in Clinical Practice Guidelines for Pain, Agitation, and Delirium Rater: clinicians	10 mins
NEECHAM Confusion Scale[71]	Rate a patient's behavior while providing routine care to elderly patients Assesses cognitive processing, behavior, and physiologic functions Rater: nurses	10 mins
Nursing Delirium Screening Scale[72]	Five-item tool designed to screen for delirium during routine clinical care Rater: nurses	1 min
Delirium severity		
Memorial Delirium Assessment Scale (MDAS)[37]	Ten-item tool that measures delirium severity Rater: physicians	10–15 mins
Delirium Symptom Severity Scale[73]	Measures delirium severity Rater: clinicians	10 mins
Delirium Rating Scale[74]	Ten-item tool which evaluates symptoms over a period of 24 hours Requires training Rater: clinicians	5 mins
Tests of cognitive functioning		
Montreal Cognitive Assessment (MoCA)[39]	Assesses different cognitive domains for rapid screening of mild cognitive dysfunction 30 points with cut score of 26 Rater: clinicians	10–15 mins
Mini-Mental State Exam (MMSE)[38]	Measure of cognitive impairment that examines multiple cognitive domains Rater: clinicians	10–15 mins
Mini-Cog[40]	Brief screening measure of cognitive impairment in older adults to be used in primary care setting Rater: clinicians	3 mins

sampling of standardized screening tools suitable for administration in multiple settings.

When delirium is suspected, the clinician should perform a full clinical assessment. Without a formal approach to assessment, clinicians risk misattribution (i.e., wrongly assuming the patient is tired, unmotivated, or unsociable) or misdiagnosis (i.e., concluding the patient is depressed or has a personality disorder). A clinical assessment should incorporate a mental status exam, review of the medical record, and clinical history. A comprehensive mental status assessment would include the use of cognitive screening tools such as the Mini-Mental State Examination (MMSE),[38] Montreal Cognitive Assessment (MoCA),[39] or Mini-Cog.[40] Table 23.2 also lists common screening tools and their features. Online training is available for many of these tools. Cognitive screening tools adequately assess cognitive function but do not adequately distinguish between delirium and dementia.[41] Questions required for a delirium workup can seem intrusive or bothersome to patients and families, but they are necessary to establish an accurate diagnosis. Once the diagnosis is established, questions should be limited to those necessary for periodic monitoring.

Examination of the medical record should include a review of vital signs, laboratory values (see Table 23.3), imaging results, and medications to identify possible causes of delirium and the need for additional testing, if appropriate. Collateral history should be obtained to clarify the patient's cognitive baseline and substance use. The time course of the recent mental status change should be considered as well. Since the onset of delirium is usually acute or subacute, understanding the time course aids in identifying possible etiologies and helps distinguish delirium from dementia.[42]

Assessing delirious patients may be challenging when patients are unwilling or unable to cooperate with the interview and workup. Even though delirious patients present as sad, withdrawn, or uncooperative, these presentations can mask the underlying confusion. Patients may present plausible-sounding rationalizations for their behavior and inability to grasp information. Statements such as "No one told me to stay in bed," "I was saving the pill for later," "I never know the date," "I don't answer silly questions," or "The nurse didn't explain things right" should not be accepted at face value. These defensive responses may represent unconscious attempts to appear rational when confused. Delirious patients may retain social skills despite deficits in cognitive function. Such patients may respond appropriately to casual questions, such as, "How are you feeling?" however, on specific questioning they may demonstrate difficulties with insight and problem-solving. In summary, delirium is more likely to be missed when depression, social withdrawal, or lack of cooperation are predominant presenting symptoms. Delirium may also be missed when the patient's social skills are preserved. In each of these scenarios, a comprehensive clinical assessment will reveal the underlying delirium. Figure 23.1 provides a decision tree to help guide the medical workup of delirium.

Table 23.3 Laboratory values when assessing for delirium

Lab	Why it matters
Complete blood count (CBC)	Rule out infection and anemia
Metabolic profile	Rule out dehydration, hypo/hypernatremia, hypo/hypercalcemia, other metabolic derangements
Liver function	Liver failure, hepatic encephalopathy
Blood/urine toxicity	Illicit or prescription drug toxicity
Urinalysis	Urinary tract infection
Thyroid function study	Hyper-/hypothyroidism
VDRL/RPR	Tertiary syphilis
B_{12}, folate, thiamine	Vitamin deficiency
Blood gases, pulse oximetry	Hypoxia, hypercapnia, acid–base abnormalities in blood

Management

An important aspect of palliative nursing care is preventing, treating, and managing delirium. As always in palliative care, the potential efficacy of any intervention must be weighed against the burden of treatment. According to Alici, Bates, and Breitbart, an ideal treatment goal in the palliative care setting is a patient who is awake, alert, calm, comfortable, without pain, cognitively intact, not psychotic, and communicating coherently with family and staff.[33] These benchmarks are good guidelines for judging how aggressively to intervene in cases of delirium. For example, a young person with excellent baseline function who becomes delirious during chemotherapy for a poor prognosis lymphoma might be expected to recover fully from a single episode of delirium. In contrast, a delirious geriatric patient with the same poor-prognosis lymphoma and multiple comorbidities might not recover from an episode of delirium.

Rather than hard and fast rules, clinical teams are urged to evaluate the impact of medical interventions after assessment of the patient's overall circumstances and the patient's previously expressed goals of care. Healthcare professionals should help the patient and family synthesize data to achieve a clear understanding of the "big picture." A single symptom or laboratory value might distract from an accurate understanding of the overall clinical scenario. For example, it might be possible to replace hemoglobin in a transfusion-dependent patient but not prevent multiorgan failure, so, in this case, hemoglobin replacement wouldn't impact the "big picture." A clear understanding of the patient's health status is a required component of goals of care discussions, but healthcare professionals should not wait for such discussions to clearly communicate the patient's complex health issues in relationship to treatment benefits and prognosis. For interventions to be considered beneficial, they must be achievable without undue patient burden and be sustainable for a meaningful period of time. Correcting primary causes of delirium may completely or partially resolve many instances of delirium and remains the preferred strategy when clinically and ethically feasible.

Healthcare professionals should enlist the family's assistance in caring for the delirious patient. Recognizing the complex nature of the modern family and the multitude of caregiving arrangements, the authors will use the terms "family" and "caregivers" interchangeably. Family members may understand the patient in ways healthcare professionals cannot. Seek input about the patient from family members; consider family to be experts on the patient's premorbid functioning. Caregivers may hesitate when they feel unsure about what to do. Involving the family fosters continuity in patient–caregiver relationships, reduces feelings of helplessness, and relieves some of the staff's burden. Caregivers will be

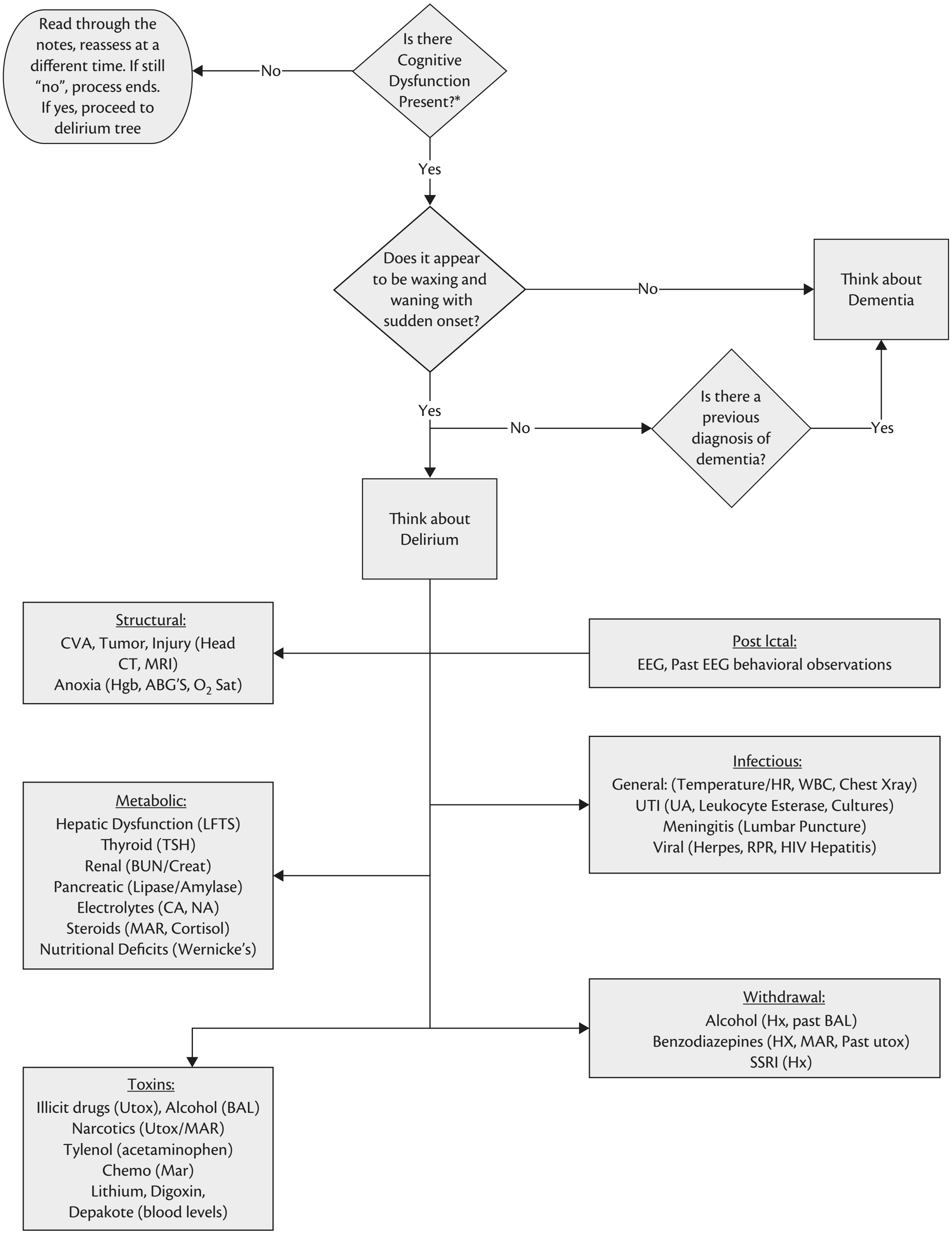
Is there Cognitive Dysfunction Present?*
No
Read through the notes, reassess at a different time. If still "no", process ends. If yes, proceed to delirium tree
Yes
Does it appear to be waxing and waning with sudden onset?
No
Think about Dementia
Yes
No
Is there a previous diagnosis of dementia?
Yes
Think about Delirium
Structural:
CVA, Tumor, Injury (Head CT, MRI)
Anoxia (Hgb, ABG'S, O2 Sat)
Post Ictal:
EEG, Past EEG behavioral observations
Infectious:
General: (Temperature/HR, WBC, Chest Xray)
UTI (UA, Leukocyte Esterase, Cultures)
Meningitis (Lumbar Puncture)
Viral (Herpes, RPR, HIV Hepatitis)
Metabolic:
Hepatic Dysfunction (LFTS)
Thyroid (TSH)
Renal (BUN/Creat)
Pancreatic (Lipase/Amylase)
Electrolytes (CA, NA)
Steroids (MAR, Cortisol)
Nutritional Deficits (Wernicke's)
Withdrawal:
Alcohol (Hx, past BAL)
Benzodiazepines (HX, MAR, Past utox)
SSRI (Hx)
Toxins:
Illicit drugs (Utox), Alcohol (BAL)
Narcotics (Utox/MAR)
Tylenol (acetaminophen)
Chemo (Mar)
Lithium, Digoxin,
Depakote (blood levels)

Figure 23.1 Delirium decision tree.

Source: Jennifer Peltzer-Jones, PsyD, RN, Senior Staff Psychologist, Department of Emergency Medicine, Henry Ford Health System, Detroit, Michigan. Copyright by Dr. Jennifer Peltzer-Jones.

more willing to assist if they understand the rationale for their caregiving role, which may be emotionally uncomfortable and require new learning. Of note, caregiving may exacerbate preexisting tensions within the family unit. For instance, an adult child may be placed in the role of providing care for a parent she dislikes or with whom she has had a traumatic history. Sometimes out-of-town relatives continue to demand burdensome interventions long after local caregivers have shifted preferences to palliative measures. Healthcare professionals should anticipate family tension, attempt to identify the nature of the strain, and coach family members as part of routine comprehensive care.

The following case study highlights the multiple considerations in the care of the delirious patient. Some of these considerations have been previously described in the assessment section of the chapter. Other aspects of delirium, such as pharmacological and nonpharmacological treatments and family issues, will be discussed in subsequent sections of this chapter.

Case Study: A Patient with Delirium

CM was an 86-year-old woman with moderate dementia, anxiety, and a prior history of depression. She developed chest pain and confusion, was hospitalized and found to have suffered a myocardial infarction, her second. She remained confused. Further neurological workup revealed embolic strokes, but not of a sufficient size to adequately explain her delirium. Lab values were within normal limits. Because of her confusion, the patient's diazepam had been held, but now diazepam was resumed at her outpatient dose of 5 mg twice daily orally because of concerns about possible benzodiazepine withdrawal. Her confusion did not improve.

Code status was discussed with the patient's elderly spouse at the time of admission, late at night. He requested she be a full code. After subsequent discussions with nursing staff, it was clear the spouse, though highly educated, did not grasp the concept of code status. He said, "I don't want her to linger and suffer; if her heart stops, I want the code to be 'full' so they don't bring her back just 'part way.'" Clarification of the meaning of full code resulted in code status being changed to Do Not Resuscitate (DNR). Though she was DNR, the husband did not want her to "starve to death," so a feeding tube was placed.

Initially CM had lucid intervals when she spoke coherently to family members. CM had always had a difficult personality. One of her children commented that during her lucid intervals she was "nicer than she had ever been." Her delirium became persistent however, as she continued to deteriorate. She became agitated and aggressive, scratching and kicking at staff, and required restraints. Her spouse was concerned that she was aggressive because she was angry with her husband for bringing her to the hospital. After meeting with CM's nurse, the spouse seemed to benefit from an explanation of delirium and its symptoms, and understood his wife's aggressive behavior was probably not a meaningful attempt to communicate. The husband accepted a plan of care for comfort only and stopped insisting on tube feedings.

CM was started on quetiapine, and, at a dosage of 25 mg orally, at bedtime she became calm and only mildly sedated. She was then stable enough for discharge to home hospice care. She died peacefully there, with her husband at the bedside. He regretted there had been no deathbed resolution of their lifelong issues, blaming himself for CM's chronic unhappiness. He was reassured by staff and realized now that making peace with her would have to come from within himself.

Pharmacological Management

There is no pharmacological treatment for delirium itself,[15] but medications can be useful for managing symptoms that are distressing or interfere with care (see Table 23.4). Medications that can cause delirium, like anticholinergic drugs, steroids, and cannabinoids, should be avoided or used with special care in delirious patients.

When agitation, aggression, and paranoia occur in delirium, they can be effectively treated with antipsychotic medications.[33] Commonly used agents include quetiapine, risperidone, and haloperidol. The antipsychotics are equally effective for treating agitation, aggression, and paranoia.[43] For many clinicians, quetiapine is a first choice because it is least likely to cause extrapyramidal symptoms, such as muscle rigidity and tremor. The extrapyramidal symptom of akathisia can cause motoric overactivity, an urge to move that can resemble agitation. Quetiapine also has the potential advantage of being sedating. Risperidone, a more potent dopamine blocker than quetiapine, has greater risk of extrapyramidal side effects. Haloperidol, an older, high-potency antipsychotic, can be readily administered orally or intramuscularly and, in some settings, intravenously. Haloperidol is the standard treatment for acute agitation.

Benzodiazepines like lorazepam can reduce agitation but must be used with caution because they can cause delirium.[17,44] Benzodiazepines act on the GABA neurotransmitter system, which is widely distributed in the frontal lobes. Thus, benzodiazepines can cause behavioral disinhibition in much the same way alcohol does and must be used with care in delirious patients. The high-potency, short-acting benzodiazepine midazolam is sometimes used to produce complete sedation in agitated ICU patients. Benzodiazepines can also aid in reducing anxiety, regulating the sleep–wake cycle, and managing symptoms related to alcohol and central nervous

Table 23.4 Common medications used in the pharmacological management of delirium

Medication role	Medication type	Generic/brand name	Dose range/route
Agitation/psychosis	antipsychotic	Haloperidol/Haldol	0.5–5mg 2–3 times daily, PO/IM/IV
		Quetiapine/Seroquel	25–150mg daily PO
	benzodiazepine	Risperidone/Risperdal	0.25–2mg daily PO
		Lorazepam/Ativan	1–2 mg 3–4 times daily PO/IV
Alcohol/sedative withdrawal	benzodiazepine	Lorazepam/Ativan	1–2 mg 3–4 times daily PO/IV
Sleep–wake disruption	hypnotic	Zolpidem/Ambien	5–10 mg at bedtime PO
	hormone	Melatonin	3–6 mg at bedtime PO
Mood regulation	antipsychotic/mood stabilizer	Quetiapine/Seroquel	25–150 mg daily PO
	antidepressant	Escitalopram/Lexapro	5–10mg daily PO

system depressant withdrawal. Benzodiazepines, specifically lorazepam, are also very effective in treating catatonia. Benzodiazepines used in conjunction with haloperidol can be more effective for treating agitation than haloperidol alone.[45,46]

Delirious patients in whom affective symptoms, like tearfulness and weepiness, are prominent can be treated effectively with antidepressants, especially selective serotonin reuptake inhibitors (SSRI). End-of-life care sometimes requires high doses of pain medications, which can cause excessive sedation. Stimulants like methylphenidate can have a role in managing excessive sedation, although there is not enough evidence to recommend psychostimulants as standard treatment for hypoactive delirium.[33]

Some researchers have explored whether prophylactic use of antipsychotics, alpha-2 agonists, or melatonin might prevent delirium. Results in ICU and acute care studies have been mixed, with data suggesting need for further study.[12,23,33,47] Early research suggests that the alpha-2 agonist dexmedetomidine can be effective in both the treatment and prevention of delirium.[48] The use of dexmedetomidine may reduce postoperative delirium by as much as 50%.[48–51] However, the cost of dexmedetomidine has limited its widespread use.

Nonpharmacological Management

A wide array of nonpharmacological interventions may prevent delirium or limit its severity and duration.[5,15,47,52–54] Interventions which optimize overall functioning and thus prevent or mitigate delirium severity include preventing dehydration, optimizing nutrition and elimination, preserving sleep–wake cycles, maximizing mobility, and preventing or treating pain.[17,20,55] Limiting delirium-promoting medications and preventing or aggressively treating infection, electrolyte abnormalities, and hypoxia can reduce the incidence and severity of delirium.[20,56–58] Minimizing time on ventilatory support through frequent weaning challenges has been found to decrease the incidence and duration of delirium.[58,59] Finally, environmental interventions which facilitate sensory perception and communication have proved helpful.[6,15] Using environmental cues to maintain orientation, employing aids to overcome sensory impairment (e.g., glasses, hearing aids), and involving family in the patient's care are examples of environmental interventions. Evidence regarding the efficacy of nonpharmacological treatment has been mixed. However, many studies in ICUs, medical/surgical acute care, palliative, and hospice settings have shown a decrease in the frequency and duration of delirium in response to these interventions.[5,20,47,52–54,56] Interventions to prevent delirium have also resulted in other benefits including limiting decline in cognitive function among patients with preexisting cognitive impairment, fewer falls, and decreased use of hypnotics.[13,15,60]

Management

Since delirium is a global and fluctuating disorder, nursing care involves anticipating problems, not just responding to the patient's momentary performance status. Central to all interventions is establishing and maintaining a therapeutic alliance with the patient. Clinicians who cultivate a therapeutic relationship with patients (and their caregivers) will ease distress more successfully than those who focus on correcting the patient or enforcing rigid approaches to care.

Delirious patients may become difficult or socially inappropriate, causing caregivers to feel angry or embarrassed. Caregivers should understand that helping their delirious relative does not represent approval of present or past behaviors. Although a patient's behavior evokes unpleasant feelings in caregivers, a delirious patient can rarely control his or her behavior. Additionally, caregivers should be encouraged to care for themselves by realistically appraising their own needs and accepting help from others, rather than feeling guilty about their own limitations.

Safety

The healthcare team or family must assume ultimate responsibility for the patient's safety. With impaired cognition, patients often act impulsively or make ill-advised decisions. Patients may not understand, believe, or remember explanations about their own care, especially limitations on their autonomy. One should expect difficulties with eating and personal hygiene, attempts to dislodge tubes, neglect of ambulation restrictions, and wandering or efforts to leave against medical advice. Ensure tubes are in place, cover tubing so patients aren't distracted by it, reposition dislodged oxygen cannulas as needed, track and ensure adequate nutritional intake, encourage periodic toileting, track urine output, help the patient change positions, and maintain optimal mobility.

Physical restraints should be avoided, as recommended in the "Choosing Wisely" guidelines published by the American Geriatrics Society in April 2015.[61] Restraints can increase agitation, cause physical injury, and worsen psychological distress.[62] However, there may be rare instances when restraints are necessary. Each healthcare system should develop and adhere to guidelines for the safe and appropriate use of restraints, understanding that there are usually preferred alternatives including one-on-one monitoring and care provided by family or trained personnel. Ensuring safety absolutely includes preventing access to weapons, particularly firearms. Firearm access can be uncomfortable for healthcare professionals and caregivers to address.

Delirious patients aren't always agitated, but their unpredictable behavior mandates preparation for extreme scenarios. For example, delirious patients have been known to try escaping from moving cars while on the way to medical appointments. Providing simple explanations to the patient just prior to travel and asking a family member or friend to accompany the caregiver can help assure safety and limit caregiver burden. Consider enlisting the guidance of home care professionals if they are already working with the patient.

Communication

With difficulty attending to and processing information, even simple directions and explanations may puzzle, frustrate, or overwhelm the patient. Delirious patients may behave as if in their traditional roles (e.g., parent, executive) despite cognitive impairments. Patients may insist on illogical or unrealistic requests. Families who understand the nature of delirium will appreciate why they must act in the patient's best interest, even if this upsets the patient. Rather than feeling guilty for refusing their loved one, families can feel good about doing the right thing for their loved one in their time of need.

It is important to understand the purpose of your communication with the patient. For assessment purposes, some challenging questions may be necessary. Otherwise, therapeutic interventions should be calming and reassuring. Keep interactions pleasant and supportive; don't force conversations. Caregivers and healthcare professionals should avoid arguing with patients, whether about facts or opinions. State facts once in a noncritical, gentle manner.

If the patient tolerates inquiries, then simple concrete questions can be asked. It is reasonable to ask, "Are you in pain?" "May I give you a bath?" It is likely not helpful to ask, "What did the doctors say during yesterday's family meeting?" or explain, "Your sodium is low, and we're wondering whether to discontinue one of your medications or limit your fluids." Rely on the established therapeutic relationship and a kind, nonthreatening demeanor when seeking the patient's cooperation. "It's time for your MRI now," is more likely to result in a positive response than offering a complex explanation for the test. Some patients are more cooperative when family members are present. If so, work with family to coordinate visits with essential nursing and medical care.

Teaching caregivers how to interact with the patient by observing the caregiver's actual communication style can aid in management of the patient. Reinforce caregiver behaviors which facilitate successful delirium management. Healthcare professionals should convey instructions in as positive a manner as possible by limiting corrections. The goal is to have the family remain engaged with the patient. Provide support for attempts to be helpful whether or not the patient responds as one would have hoped.

Orientation

Patients may fluctuate in their level of orientation. They may be confused about the time of day (e.g., thinking it's daytime when it's the middle of the night), date (e.g., thinking it is April when it is actually October), or year (e.g., claiming it is 1918 rather than 2018). They may be disoriented to place (e.g., thinking they're home rather than in the hospital or that they've been taken to a jail rather than a healthcare facility). Usually patients know who they are, but may deny some aspect of their situation (e.g., "I'm not sick"). Disorientation sometimes includes not recognizing people they are familiar with. Gentle reorientation (e.g., "What a beautiful Fall day. I can see the leaves changing from your hospital window") is preferred to any attempts at orientation that upset the patient. Make use of clear environmental cues: light (natural, when possible) during the day, darkened room at night, visible clock and calendar, date and name of nurse on message board in the room. Avoid pressuring patients by repeatedly correcting them or excessively inquiring into orientation. Explain to caregivers how orientation counters feelings of disorganization and helps anchor patients so they can make sense of the world and feel less overwhelmed.

Sleep–Wake Disturbances

Sleep–wake disturbances in delirium can be difficult to correct. The delirium itself, lack of daytime stimulation, noisy nighttime environment, and bedrest may disrupt the ability to fall asleep, remain asleep, return to sleep after waking during the night, or awaken rested. Patients may get up in the middle of the night and begin unsafe, unsupervised tasks (e.g., cooking, house cleaning, hobbies), wander outside, or get in a car as if going to work. Sleep-deprived patients may be difficult to arouse during the day, resulting in missed opportunities for social interaction, nutritional intake, physical therapy, and more. The healthcare team and caregivers should facilitate clear day–night demarcation through environmental cues such as light–dark, noise–quiet, and activity–bed rest. Ensuring the patient has some activity during the day (e.g., a brief walk if health permits, moving from bed to chair, engaging in conversation with others) and a gentle transition to sleep at night (e.g., warm beverage if taking oral fluids, massage, dim lighting if a darkened room is upsetting, quiet surroundings, grouping of necessary medical care to decrease nighttime interruptions) can help normalize the sleep–wake cycle.

Ensuring adequate pain management is essential for decreasing agitation during the day and promoting sleep at night. When sleep disruption is severe, hypnotic medications may be necessary (see the section "Pharmacologic Management") even though hypnotics themselves may exacerbate delirium. Family members can help with time-consuming interventions such as keeping the patient awake and engaged during the day. Explain to families why awakening the patient is usually a better option than letting the ill person rest all day. Families can help prepare the patient for sleep by tidying the environment, playing quiet music, and offering gentle massage. When a full-body massage is impractical or unwanted, simply massaging hands or feet can be enough to soothe the patient. Normalizing sleep–wake cycles is an important goal except during a terminal delirium when death is imminent.

Environment

Calm, soothing environments can be beneficial in managing delirium. Delirious patients may perseverate on some aspects of their environment while ignoring other cues. Distorted perception is common. Patients may attribute meaning to innocuous background noise, misinterpret the identity of persons or items within their visual field, or experience frightening hallucinations. Placing familiar photos within view, encouraging the presence of family and friends, limiting the number of visitors at one time, providing consistent staff, and encouraging quiet conversation may be helpful. Ensuring the patient has access to assistive devices such as eye glasses, hearing aids, and dentures can help patients interact with the environment, feel safe, and decrease agitation. Familiar music can also soothe patients struggling to make sense of their environment. Take cues from the patient. That which is disturbing to one may be comforting to another. Sometimes variety helps relieve feelings of being closed in or trapped. A family member may be able to take the patient for a short walk or ride to enjoy a different view if the patient is calm enough to cooperate. Unfortunately, changing locations may also be disorienting for delirious patients who frequently misinterpret unfamiliar stimuli. Hospitalized patients may protest being taken from their rooms for procedures or tests. It helps if family or staff accompany patients to offer reorientation and reassurance.

Behavioral Interventions

Knowledgeable caregivers must adapt the environment to meet the patient's needs and adjust communication to match the patient's cognitive capacity. Covering tubing so the patient doesn't try to dislodge it or simplifying conversation so the patient remains calm are two examples of caregiver behaviors that can help delirious patients. While shared decision-making is a laudable goal, behavior modification techniques requiring patient insight and executive function have little role in the setting of delirium. For example, contingency limit-setting (e.g., "If you do x, I will do y") will only frustrate the delirious patient incapable of understanding complex instructions. Likewise, punishment, sometimes rationalized as a "consequence" for undesirable behavior, rarely improves the situation.

Goal-Setting

With impaired memory and executive function, delirious patients become easily overwhelmed. In delirium, it can be helpful to prioritize the multiple nursing and other medical care tasks. Some clinical tasks are more important than others. For example, if patients refuse a full bath, limit care to essentials to prevent infection and skin breakdown. Use enticements that appeal to the patient, rather than scientific logic. For example, "Let's get you dressed up for your wife's visit," might be more appealing than, "You haven't bathed in two days. That's not going to help you recover." If feeding is difficult, make sure foods are high value (i.e., high calorie, high protein, etc.) for maximal dietary efficiency. If the patient tends to refuse procedures, it may be helpful to schedule procedures in order of priority.

Collaborative Care and Clinical Pathways

Causes of delirium are usually multifactorial. Therefore, management interventions should target the multiple risk factors for the syndrome[33] as described throughout the "Management" section of this chapter. When these interventions are combined into single protocols or care pathways, they are referred to as *multicomponent* or *bundled interventions*. Sometimes known by their acronyms (e.g., HELP for Hospital Elder Life Program[60] and ABCDE + F for Awaken, Breathing, Choice of Sedative, Delirium Detection, Exercise, and Further Care[55,58]), multicomponent interventions usually share key characteristics, even though specific components vary. Bundled interventions stress (a) integration of delirium protocols into routine care; (b) adherence to all aspects of the protocol; (c) multidisciplinary participation from nurses, physicians, pharmacists, rehabilitation therapists, and relevant specialists for assessment and treatment; d) collaboration and coordination via team rounding, consultation, and documentation; and (e) sometimes inclusion of family or volunteers to implement parts of the intervention. In addition to assisting with direct patient care, family members may help track the patient's progress and communicate aspects of the treatment plan to other family, friends, and even healthcare professionals who interact with the patient. Benefits of implementing multicomponent interventions varied from decreasing the incidence of delirium to mitigating the severity and negative sequelae of the syndrome, to decreasing healthcare costs.[15,20,47,53–58,60,63,64]

Despite the prevalence of delirium, many healthcare professionals lack sufficient knowledge to understand, assess, diagnose, prevent, and manage delirium.[3,4,21,63,65–68] Since education alone is rarely sufficient to change practice, the use of protocols or clinical care pathways is recommended for the prevention, diagnosis, and management of delirium.[59]

Legal and Ethical Considerations

In those nations where adults are treated as autonomous individuals, patients have the right of self-determination, including control over their own bodies. When a patient's ability to exercise informed judgment is in doubt, certain healthcare professionals may be granted the legal authority to evaluate the patient's decision-making capacity. These healthcare professionals determine capacity by evaluating whether a patient is capable of understanding (1) the nature of a problem, (2) that a decision has to be made about the problem, (3) the consequences of the various clinical decisions, and then (4) whether the patient can integrate the necessary information to arrive at a decision consistent with the patient's values.[69] For example, to demonstrate capacity, a patient might need to recognize his diagnosis of kidney failure, understand why dialysis is being offered, consider the sequelae of accepting or declining dialysis, and then consider which decision fits more closely with his values or goals of care.

Delirious patients, by definition, have difficulty performing the four cognitive tasks required to maintain capacity. Of note, capacity is always narrowly defined. "Capacity for what?" is the operative question. Some patients lack capacity in a global way. Others may retain capacity in certain limited circumstances. Failure to recognize lack of capacity leaves delirious patients vulnerable to making uninformed and potentially harmful decisions which the patient would not have made if able to think clearly. If a patient appears confused or makes decisions a reasonable person would not have made, it is the healthcare team's responsibility to initiate a capacity evaluation as part of the care of the delirious patient.

That said, patients *with* capacity have the right to make ill-advised decisions, although caring professionals should attempt to inform, caution, and even persuade competent persons to make choices consistent with the patient's values. When a person lacks capacity, protection must replace persuasion. It isn't ethical or safe to rely on persuasion when a patient's cognitive capacity is too compromised to understand or cooperate. Protection takes the form of surrogate decision-making through identification of durable power of medical attorney, an identified medical patient advocate, or a court-appointed guardian ad litem. Most states have established hierarchies by statute for designating which relative becomes the official surrogate if the patient has not previously identified an advocate. Challenges arise when designated decision-makers disagree with other involved caregivers or when decision-makers lack some of the attributes of ideal surrogates (i.e., interested, involved, knowledgeable, caring, without personal agendas, and devoted to exercising decisions consistent with the patient's values and wishes).

Capacity, a clinical status determined through assessment by a healthcare professional, is distinguished from *competency*, a legal status which can only be determined by a court. In the United States, laws vary by state. Typically, Probate Courts process applications to declare a person incompetent and in need of a guardian. The procedure involves providing a court-appointed advocate for the patient to ensure patients do not lose their rights because of the whims of others or simply because the patient disagrees with medical advice.

In addition to questions of capacity and competency, a common ethical challenge in the setting of delirium is the question of whether certain medical interventions are appropriate, even when the healthcare team, patients, or families request these interventions. This issue is addressed in the "Nonpharmacological Management" section of this chapter. When questions about goals of care, beneficial/nonbeneficial treatment, capacity, and competency arise, consult with experts in palliative medicine, behavioral health, bioethics, or similarly prepared individuals who can provide guidance to the primary team.

Conclusion

Delirium is a common and important problem in the palliative care setting. Though delirium is sometimes an unavoidable consequence of severe illness and complex care, it may be possible to prevent delirium or mitigate its consequences. The use of systematic screening and clinical care pathways are highly recommended. Early recognition and appropriate treatment can avoid some of the severe burden this disorder imposes on patients, caregivers, and healthcare systems.

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CHAPTER 24

Insomnia

Karla Schroeder

Key Points

- Insomnia is a symptom of impaired sleep that is characterized by inconsistent or ineffective sleep patterns.
- Assessment is a key component in the identification of insomnia.
- It is important to control insomnia symptoms for persons with serious illness.
- The plan of care should directly address the cause of insomnia.
- Cognitive-behavior therapy (CBT) is the first-line treatment for insomnia, with pharmacological interventions used as appropriate.

Introduction

Suffering from insomnia is an everyday problem for those with serious illnesses.[1–7] Comorbid conditions as well as symptomatology often contribute to insomnia. For the palliative care population, poorly managed insomnia is reported as a widespread symptom.[1–3]

Management of insomnia requires understanding and assessment of the multidimensional elements of the condition. These include the physical, emotional, psychosocial, and spiritual aspects affecting quality of life (QOL) and care.[1,2,5–7] Although insomnia is a common symptom of persons with serious illness, it remains undermanaged, and research is limited. This chapter provides a model for assessment and intervention, using a holistic approach to care for those who suffer from insomnia due to a serious illness.

Definition of Insomnia

The American Academy of Sleep Medicine defines insomnia as a subjective, self-reported experience.[3] Insomnia is characterized by chronic dissatisfaction with sleep quantity or quality, typically associated with difficulty falling asleep, frequent nighttime awakenings with difficulty returning to sleep, and/or awakening earlier in the morning than desired.[1,3–11] Insomnia is further characterized by its symptoms: functional daytime impairment such as fatigue, sleepiness, cognitive impairment, and disturbances in mood.[1,3–5,7,9–11] Insomnia is considered chronic if sleep disturbances occur more than three times per week, for a period longer than 3 months. These adverse effects can lead to a significant impairment to QOL.[1,7,12,13]

Diagnosis

Criteria for diagnosing insomnia based on the International Classification of Sleep Disorders include difficulty initiating and/or maintaining sleep and/or early waking/awakening.[1,3,5,6] This equates to 20–30 minutes or more of sleep latency.[1,3,5,6] Difficulty with sleep occurs despite adequate opportunity and circumstances to sleep which are not explained by another disorder.[1,3,5,6] Additional criteria include some type of daytime impairment due to difficulty with sleep. Daytime impairment related to difficulties in sleep may include fatigue, malaise, difficulty concentrating, memory impairment, or alteration in mood.[1,3,5,6]

Prevalence and Impact

Insomnia is among the most prevalent, distressing, and undermanaged symptoms experienced by persons with serious illness.[1–7] The prevalence of insomnia and associated symptoms in seriously ill persons is estimated at 70%.[6,12] However, prevalence of sleep disturbances for patients with serious illness varies by diagnosis. This equates to 24–95% of persons with cancer, 50% of persons with pulmonary disease, 35% of persons with heart disease, and 75–95% of persons with Parkinson's disease.[1,4,6,12,14] The wide error in margin may exist due to underreporting. Insomnia is associated with increased rates of depression, decreased QOL, and increased fatigue in persons with serious illness.[1,10] Further effects of poor sleep patterns include increased risk for anxiety, depression, cardiac disease, and increased mortality.[1,4,9,10] Without intervention, insomnia remains consistent from time of diagnosis throughout the trajectory of the illness.[1]

Case Study: A Patient with Insomnia

A 50-year-old woman was seen by her home health nurse. She had complaints of sleepiness during the day and the inability to sleep at night. Through further assessment and information gathering, the home health nurse noted a diagnosis of congestive heart failure and chronic obstructive pulmonary disease (COPD), along with use of an angiotensin-converting enzyme (ACE) inhibitor, diuretics, and bronchodilators. The woman told the nurse she felt "jittery," got up at night to urinate, and that "taking all that medication before bed makes my stomach hurt." The nurse asked her to expand further on her bedtime routine. She discovered that the patient often watched TV, then changed into her bed clothing and took her medications, including diuretics and bronchodilators at around 9:00 P.M., prior to going to bed. She also noted that she did not fall asleep until after midnight, awakened around 10:00 A.M., then was napping from 2:00 P.M. to 5:00 P.M. to make up for lost sleep. She also reported that her inability to sleep worsened after her husband passed away 6 months ago. She told the nurse that she had been with her husband for 25 years and had not slept alone since they were married. She expressed fear related to his end-of-life journey and concern as to how her life journey would end.

This case presents many potential causes of insomnia, including physical, emotional, spiritual, social, and treatment-related issues which could contribute to the woman's inability to sleep.

Pathophysiology

The pathophysiology of insomnia consists of multiple factors which include complex biological coordination and genetics.[1,5,11] Understanding the pathophysiology of insomnia for the individual may guide potential treatment options.[1,5,9,11,15]

Insomnia is multifocal and may coexist with physical, social, spiritual, and emotional components. Insomnia may be associated with stress, medications, substance use, poor sleep habits, or the environment.[1,3,5–9,11,15] Risk factors for insomnia include being female, older, or possessing certain comorbid conditions, personality traits, menopausal symptoms, or hyperarousal.[1,9,15]

The sleep cycle is a highly structured and well-organized activity following a circadian period.[1,5,9,11] The circadian rhythm directs the sleep–wake cycle and is regulated by a combination of biological processes and environmental factors.[1,5,9,11] Interruption of circadian rhythms may be a factor in insomnia.

Research also shows that patients with insomnia have higher day and night body temperatures, urinary cortisol, adrenaline secretion, and adrenocorticotropic hormone (ACTH) than patients with normal sleep patterns.[9] Insomnia is most likely to develop in those who have increased genetic risk and who experience abnormalities in neurobiological processes.[9]

Contributing Factors for Insomnia

Physical Factors

The preceding case study provides an example of insomnia as it correlates to comorbid conditions and treatments. Comorbid medical conditions which may increase the prevalence of insomnia include stress, asthma, COPD, gastroesophageal reflux disease (GERD), chronic pain syndromes, obesity, congestive heart failure (CHF), angina, hyperthyroidism, restless leg syndrome, or diabetic neuropathy.[3,4,9,10,15,16] Persons with serious illness may have shortness of breath, pain, fear, anxiety, and/or urinary frequency associated with these illnesses.[1,10] Lack of symptom control has been reported to be one of the most prevalent reasons for insomnia in the palliative care population.[1] Additionally, the treatments used during care for persons with serious illnesses may cause insomnia. Medications such as corticosteroids, bronchodilators, caffeine, chemotherapeutic agents, amphetamines, anticonvulsants (phenytoin), or diuretics may negatively impact the ability to rest without disturbance.[1,2,10,16,17]

Assessment for Physical Factors Contributing to Insomnia

When performing a thorough insomnia assessment, a holistic approach should be used to detect causes of impaired sleep patterns (Table 24.1). The physical and medical assessment includes a general medical, psychiatric, and determination of comorbid conditions.[2,5,16,17] The initial clinical assessment should focus on reversible factors which may be contributing to a sleep disturbance.[2,3,5,16,17] Box 24.1 outlines the essential

Table 24.1 Selected tools to assess sleep

Tool name	Description
Insomnia Symptom Questionnaire	Assesses and characterizes symptom burden
Insomnia Severity Index	Assesses and characterizes symptom burden
Athens Insomnia Scale	Assesses and characterizes symptom burden
Iowa Sleep Disturbances Inventory	General screening tool. Identifies underlying factors which contribute to the symptoms of insomnia to direct initial treatment recommendations
Auckland Sleep Questionnaire	General screening tool for contributing insomnia factors Identifies underlying factors which contribute to the symptoms of insomnia to direct initial treatment recommendations
Pittsburgh Sleep Quality Index	Useful screening tool Limited accuracy for specific sleep disorders
Global Sleep Assessment Questionnaire	Useful screening tool. Evaluates for seven different types of sleep disorders: insomnia, insomnia with mental disorders, shift work sleep disorder, sleep apnea, restless leg syndromes, periodic limb movement disorder, and parasomnias. Low specificity Limited usefulness as a diagnostic tool.

Box 24.1 Assessment of Insomnia

1. Assessment of sleep
    a. Subjective perception of reduced sleep time
    b. Description of sleep–wake patterns and variability
    c. Timing sleep pattern disturbances
    d. Daytime sleepiness or other daytime alterations
        i. Symptoms of daytime tiredness: fatigue, napping
2. Physical assessment
    a. Neurologic exam to include symptoms of restless leg syndrome
    b. Obesity
    c. Examine head and neck: neck circumference
    d. Crowded oropharynx
    e. Lab values
        i. Ferritin, magnesium, renal function, and vitamin B_{12}
3. Symptom assessment
    a. Pain
    b. Cough
    c. Shortness of breath
    d. Urinary frequency
    e. Anxiety

(*continued*)

Box 24.1 Continued

4. Medication and substance assessment
    a. Evaluate medications which may contribute to insomnia (beta or calcium channel blockers, antidepressants, steroids, stimulants, cold preparations, herbal or over the counter medication)
    b. Use of tobacco, caffeine, alcohol, or illicit drugs·

Source: References 12, 13, 20–24

components of the physical assessment.[3,5,15–18] The individual should be consulted in determining the most appropriate treatment modality.

Nursing Intervention for Physical Factors Contributing to Insomnia

In the case study presented earlier, the nurse first inquires about the physical aspects of insomnia: the sleep–wake cycle, sleep hygiene, and treatment-related issues. The nurse should counsel the patient about taking medications that may inhibit sleep earlier in the day, as opposed to directly before lying down. The nurse could instruct the woman to use the twice-daily bronchodilators when she awakens in the morning and at supper time and to take her once-daily diuretic in the morning. This will reduce the number of times the patient is awakened to use the bathroom and decreases bedtime "jitters" due to medications. Other instructions could include decreasing the amount of fluids in the hours prior to bedtime, avoiding caffeine after noon, or placing pillows in pain points. Taking a shower or bath before bedtime can assist with creating a bedtime routine as well as improving relaxation and decreasing pain. The nurse may suggest a referral to a licensed mental health professional for cognitive-behavioral therapy (CBT).[4,5,7,13,18,20,21] If such changes along with CBT do not work, a pharmacological intervention may be necessary.[1,3,5–7,9,11,13,17,18,20,21]

Environmental Factors Contributing to Insomnia

People with serious illness may also experience sleep pattern disturbances that are related to treatment locations, diversion from normal sleep routines, and light, as well as unfamiliar or noisy environments.[5,15,17,18] For example, the person may experience frequent hospitalizations which can exacerbate insomnia and/or other symptoms.

Assessment for Environmental Causes of Insomnia

The person's sleep environment should also be assessed to remove obvious stimuli and create an atmosphere conducive to sleep.[5,6,7,11,16–18,20] Environmental assessment should include:

- Light
- Noise
- Phone, computers, tablets, and other electronic devices
- Hospitalization
- Moving to an unfamiliar environment
- Television

Nursing Intervention for Environmental Factors Contributing to Insomnia

The nurse should inquire about the patient's bedtime, waking time, and napping time. She could instruct the person to decrease daytime napping and/or to nap earlier in the day. This would promote improved sleep–wake patterns. The nurse should instruct the patient to remove extraneous environmental stimuli and reduce noise stimuli by turning off the television; decreasing the number of visitors during the time of sleep; reserving the bedroom for sleep and sexual activities as opposed to reading, television, crossword puzzles, video games, or other mentally stimulating activities; and reducing the amount of light by using blackout curtains or removing unnecessary lighting. A night light in the bathroom instead of a bright overhead light will decrease stimuli at night. For the hospitalized patient or a person receiving around the clock care, nurses should group care tasks together to provide less environmental interruption of sleep.

Cognitive, Emotional, Existential Factors Contributing to Insomnia

Insomnia may also be caused by cognitive, emotional, and existential factors. Persons with chronic insomnia appear to have hyperarousal or increased somatic cognitive and cortical activation within the brain.[9] This also has been described as cognitive and emotional hyperarousal at night.[9] Hyperarousal in the physiologic, emotional, or cognitive networks is believed to prevent sleep regulatory processes from naturally occurring in patients with insomnia.[1,9] Persons with serious illness may also experience sleep pattern disturbances that are related to diagnosis, family, fear, anxiety, anticipatory grief, or stress.[1,2,5] Cognitive and behavioral mechanisms affect insomnia regardless of how insomnia is caused.[1,9,10,14,21,22] Persons may have misconceptions about normal sleep requirements and changes in needed amount of sleep.[1,4,6,11] This can lead to excessive worry about not having adequate sleep and create a cyclical pattern.[1,4,6,11] For example, the more a person worries about the inability to sleep, the more disrupted the sleep becomes.

Assessment for Cognitive, Emotional, Existential Factors Contributing to Insomnia

A proper assessment for insomnia should also include focus on cognitive, emotional, and existential issues which may be the cause.[5–7,10,11,16,19,20] For example, taking daytime naps, sleeping in late, or prolonged time in bed reduces the natural homeostatic drive to sleep within a person's natural circadian rhythm.[1,6,7,9,11] Patients develop a conditional arousal to stimuli that would normally be associated with sleep (i.e., heightened anxiety about going to sleep once they are in the bedroom).[1,4–7,9,11] Patients then develop a cycle in which the more they strive to sleep, the more agitated they become.[1,6,9] The patient may have ruminative thoughts or clock-watching behavior as he or she tries to fall asleep.[1] Assessment should include:

- Current or past stressors
- Sleep patterns prior to illness
- Sleep hygiene
- Fears, concerns
- Sleep–wake patterns

Nursing Intervention for Cognitive, Emotional, Existential Factors Contributing to Insomnia

In the case study, the nurse can intervene by providing instruction and supportive communication skills. The nurse would explain the importance of creating a pre-sleep routine such as going to bed at the same time every night and awakening at the same time every morning.[5–7,10,11,16,19,20]

Other ways to create improved sleep hygiene patterns include setting alarms or limiting daytime napping to 30 minutes.[5–7,10,11,16,19,20] Once a person encounters an inability to sleep, the person should rise from bed, remain in a dark room, sit up in a chair, and avoid stimuli such as the television or electronic devices.[5–7,10,11,16,19,20] This will help disconnect the bed from the inability to sleep.[5–7,10,11,16,19,20]

It is important to consider where the person is within their disease trajectory and their individual needs. Do they need to rest whenever possible based on clinical presentation? When end of life is near, provide instructions to both the patient and family regarding the likelihood of increased sleep.

When addressing emotional, social, or existential issues surrounding insomnia, consider fears of being alone, life changes, and grief, which may increase nighttime sleep difficulties. The nurse in the case study should provide supportive communication concerning the husband's death, taking the time to listen to the patient's concerns and provide social work, chaplaincy, and mental health referrals for further support and possibly CBT.

Management

Care of insomnia initially includes treatment of comorbid medical and psychiatric conditions, modifying sleep-hindering medications and substances, and optimizing environmental factors. Thus, the initial strategies for treating insomnia are to assess for underlying reasons that may be contributing to the sleep disturbance.[5–7,10,11,16,19,20]

Once the insomnia factors have been identified and addressed, treatment for insomnia may then proceed to other interventions. The treatment for insomnia for persons with serious illness should include both pharmacological and nonpharmacological interventions. The American College of Physicians recommends CBT as the initial treatment intervention for persons with chronic insomnia based on the clinical need.[1,4,5,10,11,13,21–23] Prognosis should be considered in therapeutic recommendations, as CBT takes time. If the person has a prognosis of several months, both CBT and pharmacological interventions should be incorporated into the plan of care.[1,4,5,13,21–23] Incorporating shared decision-making between patient and provider is key for successful treatment.[1,4,13,23]

Nonpharmacological Interventions

Several nonpharmacological interventions have been used for the treatment of insomnia within the general patient population. Evidence exists supporting the use of sleep hygiene, behavior therapies, and relaxation techniques. However, for persons with serious illness, limited studies are available to determine the efficacy of nonpharmacological interventions for insomnia. It is important to understand that CBT requires effort, participation, and time, which may make it inappropriate for persons who are at end of life.[4,10,13,14,21,22]

Cognitive-Behavioral Therapies

The American Academy of Sleep notes that CBT has been identified as the first-line treatment for insomnia.[4,10,13,14,21,22] For some patients, CBT therapies have produced significant improvement in the quality and duration of sleep. CBT used as part of the treatment for insomnia addresses the maladaptive processes and limits behaviors which cause insomnia.[1,3–5,10,13,14,21,22] In CBT, mental health clinicians address the relationship between thoughts, behavior, and meaning around difficulty with sleeping.[4,10,13,14,21,22] CBT works to help change unhelpful thought patterns and one's relationship to the thoughts.[4,10,13,14,21,22] Not all persons with insomnia will benefit from CBT alone. Many contributing factors such as inability or unwillingness to participate affect the successfulness of CBT.[4,10,13,14,21,22] Pharmacotherapy, in combination with CBT, should be considered for persons who are unsuccessful with CBT alone or for whom CBT is inappropriate.[4,7,10,13,16,19,21–23]

CBT to address insomnia usually consists of education on sleep hygiene, relaxation training, stimulus control, sleep restriction, and cognitive therapy.[1,4,10,11,13,14,21,22] The nurse can provide sleep hygiene education and assist with multidisciplinary team referrals.

Complementary Therapies

Complementary therapies are interventions generally not considered to be part of conventional medicine. For persons with serious illness, several complimentary therapies are available when appropriate, including massage, aromatherapy, Reiki, reflexology, mindfulness-based stress reduction, guided imagery, and/or acupuncture.[1] For some people, these therapies have improved sleep quality, duration, and efficiency; allowed use of fewer medications; and provided less daytime dysfunction.[1] Complementary therapies are based on the person's individual causes for sleep pattern disturbance and should be incorporated based on individual preference. For example, for persons whose insomnia is caused by elevated stress, some of the complementary therapies may be helpful.

Exercise Interventions

Exercise interventions involve any planned, structured, and repetitive bodily movement that are performed to condition any part of the body, improve health, or maintain fitness.[1] Exercise interventions assist with the regulation of activity and may improve the sleep–wake cycle.[1] Exercises should be completed in morning or early afternoon hours.[1] Exercise is based on the individual person's capabilities as well as clinical status. For example, passive range of motion, walking, stretching, or yoga may be appropriate.[1] Care should be taken to ensure safety during exercise. Studies have shown that exercise interventions improve mood, decrease depression, and improve the sleep wake–cycle for patients with serious illness and cancer.[1]

Several studies have noted that the use of nonpharmacologic therapies is first-line treatment for insomnia and may improve chronic insomnia, mood, long-term sleep quality, and/or depression (see Table 24.2). Nonpharmacological interventions are also recommended for older persons and those who use sedating medications.

Pharmacological Interventions

Pharmacological interventions should not be first-line treatment for insomnia.[3,5,6,7,11,16,19,23,24] Recommendations regarding pharmacotherapy must be considered within the context of specific treatment goals, comorbidities, prior treatment responses,

Table 24.2 Nonpharmacologic therapies for insomnia

Drug class	Common medication	Common doses	Recommended use	Research efficacy for the improvement of sleep	FDA-approved for insomnia
Orexin receptor antagonist	Suvorexant	10 mg, 15 mg, 20 mg	Sleep onset and/or maintenance	Moderate	Yes
Nonbenzodiazepines	Eszopiclone	≥2 mg	Sleep onset and sleep maintenance	Moderate to large	Yes
	Zaleplon	≥5 mg	Sleep onset	None	Yes
	Zolpidem	≥5 mg	Sleep onset and sleep maintenance	Moderate	Yes
	Zolpidem extended-release	≥6.25 mg	Sleep onset and sleep maintenance	Moderate	Yes
Benzodiazepines	Triazolam	≥0.125 mg	Sleep onset	Moderate	Yes
	Temazepam	≥7.5 mg	Sleep onset and maintenance	Small	Yes
Melatonin agonists	Ramelteon	≥8 mg	Sleep onset	None	Yes
	Melatonin	1 mg, 2 mg, 3 mg, 5 mg, 10 mg	Not recommended	Small	No
Antidepressants	Doxepin	>6 mg	Sleep maintenance	Small to moderate	Yes
	Trazodone	50 mg	Not recommended	None	No
Anticonvulsants	Tiagabine	4 mg	Not recommended	None	No
Over-the-counter preparations	Diphenhydramine	25 mg, 50 mg	Not recommended	None	No
	L-tryptophan	250 mg	Not recommended	Small	No
	Valerian		Not recommended	Unreported	No

Source: References 1, 5, 6, 11, 17, 18, 26, 27.

availability, safety, patient preferences, and cost.[3,5–7,11,16,19,23,24] Pharmacologic management of unrelieved symptoms should be maximized if these are the underlying cause of insomnia. Medication can be used for insomnia which persists despite maximal symptom management and/or alternate treatments such as CBT.[3,5–7,11,16,19,23,24] Medications should not be used alone, but rather in conjunction with other methods of treatment such as CBT. [3,5–7,11,16,19,23,24] Medication considerations should include safety, pharmacokinetic profile, past treatments, and benefit versus harm.[4,6] Pharmacological intervention for insomnia should be used as a temporary adjunct or for persons who cannot participate in CBT.[3,5–7,11,16,19,23,24]

Caution should be taken when using pharmacological agents. For example, medication interactions, risk for falls, cognitive impairments, dependence, and adverse reactions should be thoroughly reviewed. Pharmacological agents currently approved by the US Food and Drug Administration (FDA) for the treatment of insomnia include benzodiazepines, nonbenzodiazepines, melatonin-receptor agonists, and histamine-receptor antagonists and are listed in Table 24.3.[1,3,5–7,11,16,19,23,24] Other medications which have been used to treat insomnia include tricyclic antidepressants, antihistamines, or antipsychotics because of their sedating effects.[1,3,5–7,11,16,19,23,24] Sedating medications should be carefully considered for each person based on indication for use, plan of care, and safety.

Over the past 20 years, pharmacological treatment of insomnia has declined. This may be linked to the potential for tolerance and

Table 24.3 Pharmacological interventions for insomnia

Therapy	Techniques
Sleep hygiene	Activity as tolerated with elimination of exercises 4 hours prior to bedtime. Avoid large meals Limit fluid intake in the evenings Limit caffeine, tobacco, alcohol Bedroom for sleep and sex only Maintain routine sleep–wake cycle Decrease daytime napping Decrease distracting stimuli close to time of sleep, such as noise, lights, computers, phone, television, extreme temperatures
Stimulus control	Lie down in bed for sleep only when sleepy Bedroom for sleep and sex only Avoid wakeful activities at bedtime, television, phone, eating Leave the bed if unable to fall asleep within 20 minutes, do not engage in stimulating activity, return to bed when sleepy Maintain sleep–wake cycles, set alarm, go to bed at the same time
Sleep restriction	Limit napping during the day Arise from the bed when awake

(*continued*)

Table 24.3 Continued

Therapy	Techniques
Relaxation	Imagery Mindfulness Meditation Hypnosis Yoga Abdominal breathing Progressive muscle relaxation
Cognitive therapy	Counseling Identify and replace dysfunctional beliefs regarding sleep Address overestimation and apprehension about sleep Journaling
CBT	Combination of cognitive therapies, stimulus control, sleep restriction therapy, relaxation

Source: References 1, 3, 5–7, 11, 16, 19, 23–25

dependence and increased efficacy of CBT.[3] Despite the number of medications that can be used to treat insomnia, there is little high-quality evidence to support their use.[3]

Orexin Receptor Agonists

A new class of medication with moderate supporting evidence for the treatment of insomnia are the orexin receptor agonists. The orexin receptor is a G-protein-coupled receptor that binds the neuropeptide orexin. Suvorexant is the first-in-class dual orexin receptor antagonist for the treatment of insomnia; it was approved by the FDA in 2014.[24]

Benzodiazepine Receptor Agonists

There is moderate evidence to support the use of benzodiazepines for short-term relief of insomnia in the general population.[1,3,5–7,11,16,19,23,24] However, benzodiazepines are not recommended for the treatment of insomnia for persons with serious illness as they may cause symptom rebound.[5–7,11,16,19,23] Symptoms that may increase or rebound in persons with serious illness include anxiety or agitation.[5–7,11,16,19,23] Short-acting benzodiazepine receptor agents, newer benzodiazepines, or ramelteon are recommended as a treatment of insomnia.[1,3,5–7,11,16,19,23,24] Although benzodiazepines can be effective medications, they have several unwanted side effects, such as daytime drowsiness, dizziness, or light-headedness; cognitive impairments; motor coordination; tolerance; dependence; rebound insomnia; and daytime anxiety.[1,3,5–7,11,16,19,23,24] Benzodiazepines should be used with caution and are not recommended for older persons.

Nonbenzodiazepine Receptor Agonists

Nonbenzodiazepines are the most widely used medications in the treatment of insomnia. Examples of nonbenzodiazepines include zolpidem (Ambien), zaleplon (Sonata), and eszopiclone (Lunesta).[1,2,4–6,10,12,18,19] Nonbenzodiazepines are not recommended for long-term use or older persons.[25] Nonbenzodiazepines may worsen delirium.[25]

Sedating Antidepressants

Antidepressants have been increasingly used for the management of insomnia. Tricyclic antidepressants such as amitriptyline, doxepin, trazodone, and mirtazapine may provide a sedating effect.[1,3,5–7,11,16,19,23] Caution should be exercised in using sedating antidepressants such as trazodone and mirtazapine in the older population, with a black box warning for suicidality.[1,3, 5–7,11,16,19,23,24] Other risks include falls and increase in QT intervals.

Melatonin-Receptor Agonists

Melatonin-receptor agonists appear to have minimal side effects and a decreased potential for abuse or dependence. The only melatonin-receptor agonist approved by the FDA for the treatment of insomnia at this time is ramelteon.[1,3,5–7,11,16,19,23]

Others

Other classes of medications have been used "off label" to treat insomnia, including antidepressants, antihistamines, atypical antipsychotic agents, and neuroleptics. Antihistamines such as diphenhydramine and hydroxyzine are used for their sedative properties as well as for their anticholinergic properties.[1,3,5–7,11,16,19,23] Older persons tend to have negative cognitive effects when taking anticholinergic medications and thus these are not recommended. Neuroleptics, such as thioridazine, may promote sleep in persons with insomnia associated with organic mental syndrome and delirium.[1,3,5–7,11,16,19,23,24]

Ingestible Herbal Therapies

Several ingested herbal supplements are currently being used for managing insomnia, especially chamomile, hops, lavender, passionflower, California poppy, kava kava, St. John's Wort, lemon balm, valerian, and melatonin.[1,25] Although widely used, herbal supplements do not undergo rigorous regulation or clinical trials to determine efficacy and side effects and thus are not recommended by the FDA.[1,25] The studies evaluating the benefits of herbal therapies for managing insomnia have produced inconclusive or contradictory results.[1,25] Many people use herbal over-the-counter remedies, thus it is important to have a working knowledge of them.

Conclusion

Insomnia remains a common and distressing complaint for persons living with serious illness and contributes to a decreased QOL. Physical, medical, social, emotional, and spiritual factors have been linked to insomnia. Effective management of insomnia begins with a thorough assessment that includes the exploration of predisposing factors such as unmanaged symptoms, change in usual sleep patterns, emotional stressors, comorbid conditions, and medication.

Nurses in palliative care are key investigators in helping analyze the causes of insomnia and providing interventions to assist in improving sleep. The interventions suggested after the case study may allow the individual to create improved sleep–wake patterns and sleep hygiene practices. In the case presented here, the person's social and spiritual needs were related to her husband's death, fears, and possible anticipatory grief. The suggested interventions might allow the person to have restful nightly sleep, in addition to suggesting a shorter napping period during the day.

Nurses are challenged to integrate education within the plan of care to promote healthy sleep patterns as well as advocate for appropriate multidisciplinary referrals. Unfortunately, there is little research on insomnia in patients living with serious illness. More research is needed to fully understand the etiology and treatment modalities for patients with serious illness.

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CHAPTER 25

Sexuality and Intimacy in Serious Illness and at the End of Life

Heather Shaw and Joshua Fronk

Key Points

- Sexuality and intimacy are different.
- Sexuality and intimacy are key human experiences that are impacted by serious illness and end of life.
- Palliation of sexual and intimate issues in advanced illness needs a multidisciplinary approach with attention to the physical, emotional, social, and spiritual aspects of care and quality of life.
- People with serious illness want to talk about their sexual functioning and intimate relationships.

Sexuality and Intimacy: Why They Are Different and Why It Matters

Case Study: A Patient with Congestive Heart Failure

Leo is a 75-year-old man with congestive heart failure who loves to salsa dance, work in his vegetable garden, and spend time with his wife, Rosa. Prior to and following his diagnosis, Leo experienced steady functional decline and weight loss. His symptoms, including dyspnea, required diuretics and long-acting opioids for management. Following repeated hospitalizations, conversations about hospice were initiated. Durable medical equipment (DME) was recommended to specifically improve safety in the home and help conserve energy overall. Following the recommendation for a hospital bed, Leo quietly inquired, "Would Rosa be able to lay in the bed with me?" Clarifying this response, Rosa was able to share that they had been sleeping together in the same bed for more than 50 years. Neither of them could contemplate such a big change and expressed a lot of concern about being able to sleep without lying next to one another.

The emotional and physical ties between people are a cornerstone of the human experience. Humans use their bodies to communicate emotions such as desire, affection, fear, and loss—the use of the physical person is just as powerful as the use of language. Kind words from a friend or the touch of a beloved person can turn one's day and mood for the better. Conversely, a lack of eye contact or a harsh tone of voice connotes more negative emotions and responses. The human need to communicate, to connect, and to make meaning out of life experiences holds true across the life span. In healthcare, there is an obvious focus on physical health and much time is dedicated to optimization of physical functioning. However, humans are very sociable creatures and interactions play a significant role in both physical and emotional well-being as well as in overall quality of life (QOL).[1]

The World Health Organization (WHO) currently defines *sexuality* as, "A state of physical, emotional, mental and social well-being in relation to sexuality . . . a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships."[2] While healthcare providers often see or view sexuality as the actual involvement in physical sexual activity, the definition of healthy sexual behavior varies from person to person. The perception of a healthy sexual adult varies greatly depending on one's culture. A person's preparedness for engaging in sexual activity variably starts after the onset of puberty, and the extent of one's sexual health continues to evolve and grow over time. Sexual expression is one way in which humans can express love and affection as well as feel desire and pleasure. Both sexuality and intimacy are key components of QOL, and patients value the opportunity to express these aspects up through end of life.[3]

Intimacy is a positive physical and cognitive relationship with another committed person or group.[4] This can be shared between all people regardless of age or gender. Within an intimate relationship there exists a sharing of knowledge, familiarity, affection, or bonds that continues to develop and evolve. Examples would be the simple yet powerful act of a parent lovingly putting a child to bed or a friend showing up unexpectedly to provide companionship and support. As humans get closer to the end of life, intimate moments such as these can become more powerful and cherished, proof of connection and meaning. As in the case example with Rosa and Leo, sleeping in the same bed is an expression of intimacy as well as an avenue for sexual expression. Assessment, treatment, normalization, and support for patients with serious illness who are undergoing changes in both their sexual and intimate lives are all part of the scope of a palliative care provider.

The WHO defines palliative care as "an approach that improves the QOL of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."[5] Using this definition and framework, this chapter explores how serious illness impacts sexuality and intimacy in the physical, psychosocial, and spiritual domains of health.

Impact of Physical Changes on Sexuality and Intimacy

Case Study: A Patient Struggling with Body Image Issues

Jessa is a 46-year-old woman with history of acute myeloid leukemia (AML) status post allogeneic stem cell transplantation. Eight years from her transplant, she continues to be disease-free; however, her medical course post-transplant has been complicated by chronic skin and soft tissue graft versus host disease (GVHD) which requires multiple immunosuppressive agents including chronic steroid administration. Jessa always expresses gratitude for her successful transplant; however, she also reports a significant change in her QOL. She acknowledges having depression and long-standing anxiety. She openly grieves the loss of her previous self and often states, "If my doctors had told me about the true effects of GVHD and warned me that this would be as good as my life gets, I really don't think I would have gone through with it." When asked to speak more about this, she identifies a significant change in her physical appearance and body athleticism due to chronic steroid dependence. With loss of joint mobility and strength, she is no longer able to run marathons or participate in the other athletic activities which she previously enjoyed with her spouse. During counseling sessions in clinic, Jessa discusses feeling inferior to and isolated from her partner who is still able to work out and enjoy an active lifestyle. She no longer identifies with the new person she has become.

Serious illness, regardless of disease type, can directly impact or alter sexual function. These changes are often the result of underlying disease or its associated treatment and can impact physical anatomy, sexual functioning, and identity. Alterations to sexual or reproductive anatomy can have consequences other than more obvious biologic or physical symptoms. In cancer, there may be long-term effects on sexual function and relationships solely due to effects of surgery, chemotherapy, and other cancer-related treatments. For example, women with breast cancer who undergo unilateral or bilateral mastectomy may struggle with long-term impacts on body perception and identity.[6] Similarly, young men who undergo orchiectomy to treat testicular cancer can experience incongruent body image and psychological distress.[7] Any alteration to the physical body, whether directly associated with a disease or one that is secondary to a medical intervention such as surgery, can impact the wellness of one's sexuality and intimacy. These changes can and will directly change how one is willing to share one's body. Emotional and psychiatric factors can directly result in sexual dysfunction and disturbances.[8] As in Jessa's case, the physical changes she has experienced are only one part of her overall picture. Consequences of her transplant negatively affect her self-identity as well as her ability to achieve intimacy with her partner.

Female patients who have undergone or are receiving treatment for breast cancer with surgery, chemotherapy, or hormone-blocking agents may develop low libido, dyspareunia, vaginal dryness, and loss of sensation, as well as emotional distress related to postsurgical body changes.[9] Other potential impacts include decreased or altered nipple sensation and arousal following breast reconstruction for breast cancer.[10] Treatments for pelvic and abdominal cancers often include radiation, surgery, and chemotherapy, all of which can result in chronic pain, vaginismus, and vaginal stenosis.[11] Male patients may experience low libido and erectile dysfunction as a result of prostate cancer treatment.[12] Any person, regardless of their sex or gender identity, who has undergone any combination of chemotherapy, surgery, and radiation may find permanent physical and functional changes that require adjustment in one's sexual life.

Acute or chronic illnesses that involve one or more major organ system such as cardiac, renal, pulmonary, or neurodegenerative disease can alter sexual function and expression.[13,14] Medications as outlined in Table 25.1 may decrease libido, impair orgasmic function, or have other effects on sexual health.[15–19] Patients of childbearing age may also experience a decline or loss in fertility due to surgical interventions or treatments such as chemotherapy. Many of the physical changes associated with serious illness (e.g., fatigue, pain, dyspnea, sequelae of surgery, medication side effects) can not only impact the sexual function of the body but also a person's ability to feel confident and desirable and to find pleasure and connection.

Awareness of these changes can help patients and providers speak frankly about intimacy challenges and how best to navigate them. Given the many ways in which people can express their sexuality and identity, there is no "normal" when it comes to consensual sexual expression in adulthood. The degree to which a person's sexual expression and identity is altered by serious illness will

Table 25.1 Common medication classes associated with sexual dysfunction

Medication class	Subclass	Type of dysfunction
Antidepressants	Selective serotonin reuptake inhibitors (SSRIs)	Reduced libido, orgasmic dysfunction[15]
Hormone-blocking agents	Aromatase inhibitors	Reduced desire and arousal, vulvovaginal atrophy, dyspareunia[16,17]
	Estrogen receptor modulators (e.g., tamoxifen)	Vaginal dryness, vaginal discharge, hot flashes[16,17]
	Anti-androgen medications	Loss of desire, erectile dysfunction[12,17,18]
Opioid analgesics	Chronic opioids	Reduced libido[19]

depend on the individual. Healthcare providers should not assume that, just because someone is aging or near end of life, the desire for connection or pleasure has been lost.[20,21] Healthcare providers can offer help to patients and families by reframing what sexual activity and pleasure can look like and supporting exploration of the new or changing normal.

Concrete palliative treatments do exist for physical changes that come with serious illness and at the end of life. These include medications for erectile dysfunction, vaginal lubricants, or psychostimulant medications to combat disease-related fatigue. However, there may not be specific pharmacologic treatment options available for a given symptom. Similarly, some medications may be deemed too risky or ineffective given the current state of health. In these cases, medical providers can recommend adjustments to patient-disclosed sexual behaviors or intimate patterns. Patients may need to explore other ways of experiencing pleasure that may be different from usual habits or routine.

Control of core symptoms that impact QOL such as pain, dyspnea, constipation, anxiety, and depression are important regardless of the underlying disease process. Despite scrupulous symptom management, there may be sexual side effects and changes that create issues that do not respond to traditional palliative medications and techniques. Palliative care providers should recognize the importance of developing skill sets beyond traditional physical symptom management tools. Regardless of the complexity of each case, healthcare providers can use the same communication skill techniques used to discuss end-of-life issues when assessing and exploring the health of patients' sexual and intimate health. All members of the palliative care multidisciplinary team should feel comfortable asking open-ended questions, responding to emotion, and supporting patient desire to explore difficult subjects. Counseling and normalizing the physical changes that come with dying, such as fatigue, weight loss, and physical dependence on others, as well as being present for expressions of grief and loss, should be included in the symptom management skill set. Walking with patients as they experience permanent changes in their sexual functioning and intimate relationships, assisting with adaptation, and finding ways to encourage the expression of love are all part of the role of a palliative care provider and require a multidisciplinary approach.

Serious Illness Impact on the Social, Emotional, and Spiritual Aspects of Sexuality and Intimacy

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Case Study: A Patient with a Colostomy

Maya is a 27-year-old woman with metastatic colon cancer who underwent a surgical resection of her colon as part of routine treatment, resulting in permanent placement of a colostomy. While this procedure allowed Maya to live a longer life, it came at the expense of her self-worth and identity. While many may find the tradeoff of having a colostomy for further extension of life reasonable, the adoption of a colostomy has become a permanent barrier and roadblock for Maya to live a normal, young adult life. Maya is always cognizant of the ostomy bag and its accompanying lack of control in stool passage and bowel sounds. She lives in a constant state of anxiety when around friends and family for fear of her ostomy being discovered. Maya purposely decided to stop hanging out with friends and playing volleyball, previously a huge part of her social life and identity. Body disfigurement and its associated effects on self-worth are more debilitating than the disease process itself. Maya stopped dating or pursuing relationships and often poses the question in clinic, "Why would anyone love me like this?"

The ability to connect and express affection, closeness, and affirmation in intimate relationships is just as important as physical sexual functioning. When a person is dying, intimate relationships are also changing and advancing toward the same end.[22] Coming to terms with grief and the loss of one's perceived role in life, the prior healthy functioning of the body, the old structure of family and friends, and future hopes is part of the emotional work at the end of life in intimate relationships.[23]

Part of the dying process is life review and making meaning out of one's life experience. Imbalanced or unfulfilled needs or an inability to cope with the changing nature of physical sexual functioning and the change in intimacy and closeness in relationships can all be a source of suffering as people living with serious illness approach the end of life. As seen in Maya's case, the changes wrought by her surgical interventions were in many ways worse than the fact that she was facing the end of her life at such a young age. Maya's grief for the loss of her previous body and, more importantly, her inability to make meaning out of her new life in the face of change, created a sense of existential isolation and suffering. Patients may further isolate themselves, disrupting any previously formed intimate relationships or creating insurmountable obstacles that prohibit new relationships from being formed. This type of distress is very different from traditional anxiety and depression.

The giving and receiving of closeness, intimacy, pleasure, and touch are fundamental ways in which humans find spiritual meaning and purpose as well as a sense of connectedness to one another. As people approach the end of life, it is normal to see changes such as fatigue, loss of desire, and other physical symptoms that can dampen traditional sexual expression. However, people often still desire physical closeness and intimacy, taking advantage of the opportunity to make meaning out of close relationships and find compassion for one another.[24,25] Table 25.2 summarizes how common diseases can impact both the physical as well as the psychosocial well-being of patients.[9,13,22,26,28–32]

Effects of Serious Illness on Sexuality and Intimacy through Adulthood

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Case Study: A Patient with Erectile Dysfunction

David is a 58-year-old man with advanced pulmonary hypertension. He has been living with changes to his QOL from this disease for many years. Fortunately for David, he has the added support of his partner, Glenn, in the management of his day-to-day care. Despite maximal therapy, he eventually has become dependent on continuous supplemental oxygen. His energy level remains low, and he struggles with fatigue in performing his activities of daily living. During one clinic visit, David checks off "Relationship Difficulties" and "Intimacy Issues" as concerns during a self-assessment tool. Upon encouraging David to elaborate more on why he has checked these items, he shares that he has suffered from erectile dysfunction for many years. David becomes very emotional while sharing, "I just don't feel like I am a man anymore."

Table 25.2 Common diseases and the potential effects on sexuality and intimacy

Disease group	Physiologic	Psychologic	Social	Spiritual
Cancer	*Common Symptoms*: Somatic pain, neuropathic pain, fatigue, dyspnea, nausea, and vomiting *Other Considerations*: Alterations in anatomy, body modification (e.g., ostomy, tracheostomy, feeding tube) Facial appearance changes with head and neck cancers Erectile dysfunction with prostate and urogenital cancers Sexual organ modifications with breast and GYN cancers Radiation and medication side effects such as decreased vaginal lubrication or atrophy, vasomotor symptoms, dyspareunia[12]	Mood disturbances such as anger, anxiety, depression, grief Body image disruption[9, 12]	Modification or change in relationship Disconnection from relationship[22]	Loss of self-identity Family role changes (e.g., who is primary provider for family) Decrease in self-worth Decreased sense of connectedness[26]
Heart disease, congestive heart failure	*Common Symptoms*: Dyspnea, fatigue, edema, decreased mobility, erectile dysfunction Difficulty reaching orgasm, decreased desire, decreased arousal *Other Considerations*: Connected dependence to artificial technology (e.g. IV infusions, LVADs) Scrotal and penile edema in men [27]	Depression Anxiety Self-awareness or acknowledgment of change Decreased desire secondary to treatments Low body image[13,28]	Changes in relationship Fear of rejection from partner[13]	Loss of self-identity Role changes in family (e.g., who is primary provider for family) Decreases in self-worth Loss of control Loss of meaning-making[29]
Chronic respiratory disease, COPD, pulmonary hypertension	*Common Symptoms*: Dyspnea, cough, fatigue, decreased mobility, sleep disturbances *Other Considerations*: Use of supplemental oxygen	Feelings of isolation Changes in self-esteem/body image [30]	Change in sleeping position may result in difficulty or inability to sleep adjacent to partner	Role changes (e.g., who is primary provider for family) Decrease in sense of self-worth[30]
Dementia	*Common Symptoms*: Loss of relationship memory, debility, and frailty	Loss of self-awareness Apathy and indifference to sex Can develop inappropriate and/or disinhibited sexual behavior or desires Issues of consent[31]	Loss of previously held relationship Lack of fulfillment in partner needs and desires Caregivers may ignore or pathologize sexual desire[31]	Disruption in equality of relationships Loss of sense of identity
Chronic kidney disease	*Common Symptoms*: Fatigue, debility, erectile dysfunction, impaired orgasm[32]	Depressive symptoms[32]	Demands of dialysis Concerns over fertility[53]	Role changes Meaning-making

Sexual health and intimacy change and evolve over time as one ages. People experience the creation of new intimate relationships as a normal part of aging. Some important relationships adapt to be sustained over time. For example, the relationship between a child and parent expands as the child grows into an adult. When the parent ages, there can be a reversal of roles, where the child becomes more of the supervising figure to the parent. The onset of a new disease or serious illness can and will stress intimate relationships, causing areas of distress for the patient, family, and friends. Depending on the phase of adulthood, the impacts of grief and loss on one's identity, intimacy, and other aspects of health vary. People in partnerships may experience shifts in their roles within the relationship. Other relationships may dissolve completely to give way to the formation of new ones.

Young Adulthood

Living with a serious illness like cancer, cystic fibrosis, or other genetic diseases will have effects far beyond physical health in the QOL for young adults. While identity is traditionally well established, this age group experiences a high degree of loss and regret both from reviewing past events and from looking ahead and identifying events in which one might not be able to participate.[33] For example, the young adult will experience a life review of events not yet realized, such as not being able to experience a long-term relationship, marriage, achievement of one's desired career, or having children. Young adults also may not yet be at a place in which they have been able to experience traditional one-to-one intimate relationships, and such intimacy issues can center on that loss or revolve around intimacy with friends and other family members. Young adults can feel loss and regret during life review, as well as feel remorse about not being able to experience fulfilling relationships like their peers.[34]

During this phase of adulthood, people may contemplate their own posterity and identify that they may not be able to experience parenthood. The anticipatory grief of not being able to have biological children or experience life as a parent through adoption or other means can cause considerable emotional distress. Partners of people with serious illness are also affected with the realization of this loss, which can cause a considerable amount of strain. For young adults who are newly diagnosed with cancer and are facing radiation and/or chemotherapy regimens with the very high likelihood of diminishing fertility, it is important that conversations regarding offspring be had prior to starting any therapy. Patients should be given the opportunity to meet with and obtain egg harvesting or sperm collection, thus providing future options for a biological child should this be possible or desired.[35] In addition to cancer, fertility issues can also play a role in other disease groups and genetic disorders. For example, men with cystic fibrosis are at higher risk of being infertile compared to their age-congruent counterparts.[36] Young people with renal failure report barriers to sexual partnerships and forming partnered relationships.[53]

Middle Adulthood

Similar to the young adult age group, middle-aged adults will be faced with loss from both spectrums of life. Relationships are often well established, whether they are with partners, spouses, friends, family members, or children. Relationships can be quite complex as all parties are experiencing change, which can contribute to additional distress. Partners of patients with serious illness can also experience loss in sexuality and intimacy. For example, mood disturbances, lack of fulfillment, and loss of identity have been described by partners of those with cancer.[37]

Patients and families can and will experience times of emotional distress as they cope with difficult news, physical and emotional changes, and the challenges of saying goodbye. It can be normal for patients and families to experience changes in emotional well-being at different times during an advanced disease. At the time of initial diagnosis, for example, a person can experience a wave of emotions, from surprise to anger. As one is getting closer to the end of life, there may be a sense of guilt or loss in regard to goals not yet achieved or the realization that certain goals may no longer be possible. Facing death and separation from children is a source of considerable emotional distress. Professional counseling and spiritual support can be helpful for patients and families as part of a patient-centered treatment plan.[12,38]

Older Adulthood

As people reach older adulthood, there are natural changes in body function and resilience. Regardless of disease, people will experience a slowing of one's body over time and natural changes to sexual desire and sexual response. However, sexual expression and intimate connection are part of normal aging.[20] Expressions of closeness and intimacy inform QOL and should be expected and encouraged by healthcare providers. People with cognitive impairments may still desire physical closeness and touch.[39] However, it is important to be mindful of consent issues, especially if capacity concerns become apparent. Most people will find themselves in need of physical care and support at the end of life. For some, the physical and emotional experience of caregiving can alter intimate and sexual relationships because caring for the body of a loved one is a highly intimate act. While caregivers need breaks and support, caring for a loved one can also be an immense source of closeness and intimacy. As stated by Ira Byock in his book *The Four Things That Matter Most*, "Caregiving is a burden and can exact a costly toll, but it also fills an intrinsic need that people feel to love and care for one another."[40]

In addition to physical changes, as people age, all will be faced with the inevitable death of loved ones. The longer a person lives, the more exposure to death he or she will experience: parents, siblings, partners/spouses, or friends. The loss of these different intimate relationships can be very trying for people to endure. Loss of those loved is perhaps the most universal impact of aging that all will experience.

Meeting People Where They Are, or What to Do Next

There are multiple impacts of culture on intimacy and sexuality at end of life. While it is clear that people with serious illness want to talk about their sexual and intimate lives, the current culture of healthcare, one of provider discomfort with and lack of education and experience in assessing the sexual and intimate needs of people, is a barrier.[41,42] Similar to end-of-life discussions, engaging in and talking about these topics can be difficult because they elicit insecurities and discomfort in the healthcare provider who may even omit sexual health from the assessment.[43,44]

Healthcare providers may feel unsure or unclear about what to ask and when, as well as anxiety about what to do with the answers that may be provided. They may also feel unsure about what to say to patients who are experiencing normal grief and loss reactions to changes in their bodies and relationships. They may also fear not having the solutions to questions about the impact of disease and aging on sexuality and intimacy.[45] Although many assessment tools exist for taking a sexual history, there is nothing that is validated and used generally in the palliative care population. Likewise, the traditional heteronormative social constructs of the healthcare system can be alienating and viewed as unsafe by many people, such as those in the lesbian, gay, transgender and questioning (LGTBQ) community.[46,47] Creation of a safe, nonjudgmental space where patients can express themselves is a priority.[47] Establishing a trusting relationship and a nuanced and humanistic understanding of the breadth and depth of human sexuality and connection help to break down the barriers between providers and patients with serious illness.

Both communication between healthcare providers and their patients, as well as facilitating communication between the patient and loved ones are tools that can help bridge cultural barriers, though there are few prospective studies to guide providers in determining what kind of questions to ask. Kelemen et al. asked two simple questions of hospitalized palliative care patients, "How much has your illness affected intimacy?" and "How has your illness affected your relationships?"[41,42] Checklists for physical symptoms can be implemented in practice as can using standardized sexual history tools and making questions about sexuality part of standard clinical assessment.[9,48] It is reasonable for practice settings to look at their standard assessment tools and determine what kinds of standard questions can and should be asked based on the population they serve.

The multidisciplinary team can be a way of assessing the full spectrum of a patient's physical and emotional function through the use of chaplaincy and social work, in addition to medicine and nursing. An awareness of and a movement away from a traditional conception of sexuality as only encompassing the act of heterosexual intercourse is crucial to being able to create a welcoming and tolerant environment for patients, as well as the ability to assess and support patients where they are. Instead of assuming a person has a husband or wife, instead ask if he or she has a support person, or, as suggested by Kimberly Aquaviva in her book *LGTBQ Inclusive Hospice and Palliative Care*, "Who do you consider to be your family?" or "Who are the people who are sources of emotional support for you?"[49]

A self-reflective practice that encourages a provider's self-knowledge and understanding will assist with awareness of one's own response to emotions in general and may assist with the acknowledgment of comfort and discomfort when asking and talking about sexuality and intimacy.[49] Activities such as mindfulness meditation or any practice that encourages reflection, empathy, boundary setting, and meaning in work can be helpful to palliative care clinicians who are looking to be present with their patients.[50–52] Sexuality and intimacy are key components of QOL which are impacted by serious illness and the dying process. As healthcare providers become more comfortable in addressing these important issues, patients and families will experience an improved QOL.

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CHAPTER 26

Urgent Syndromes at the End of Life

Quinten Robertson and Kelli Gershon

Key Points

- Numerous urgent syndromes can occur in the course of advanced disease, seriously affecting quality of life.
- Urgent syndromes include superior vena cava obstruction, pleural effusion, hemoptysis, spinal cord compression, hypercalcemia, and pathological fractures.
- Astute assessment and management skills are crucial to diminish distress and suffering for patients and their loved ones.

Introduction

End of life is a fragile and significant time, and palliative care can diminish distress and suffering for both the patient and the family. This chapter will discuss the following syndromes that may occur urgently at end of life: superior vena cava obstruction (SVCO), pleural effusion (PE), hemoptysis, spinal cord compression (SCC), hypercalcemia, and pathological fractures.

Superior Vena Cava Obstruction

Case Study: A Patient with Superior Vena Cava Obstruction

Mr. J, a 57-year-old man, went to the Emergency Department 1 week ago with shortness of breath and was subsequently diagnosed with non–small cell lung cancer. Before his first oncologist appointment, his wife noticed that his shortness of breath was increasing and his face was swelling. She called the new oncologist, who advised that Mr. J report to the nearest hospital.

Description

SVCO is defined as obstructed blood flow through the superior vena cava (mechanical), which is part of the venous system responsible for draining the upper extremities and head into the right atrium (see Box 26.1). The severity depends on the cause of the obstruction, which generally develops gradually, but can be emergent when SVCO occurs.[1]

Salsali and Cliffton found an SVCO incidence of 4.2% in 4,960 participating cancer patients, who are at highest risk for the illness.[2] Eighty percent of all tumors and infections that induce SVCO occur in the right thoracic region, and SVCO occurs in 5–10% of patients with infectious damage to a tissue or organ in this region. The most harmful form of SVCO occurs in people aged 40–60 years, with greater risk among males because of their higher rates of smoking-related lung cancer. Benign cases occur in individuals aged 30–40 years, but there are no gender-based differences in frequency. Because incidence of lung cancer and lymphoma differ according to race, the distribution of SVCO within the population depends on the prevalence of SVCO-inducing cancers in these communities.[3]

Pathophysiology

Tumor infiltration and thrombosis formation are the primary causes of SVCO. Compression of the superior vena cava (SVC) can result from intrinsic or extrinsic causes.[4] As a growing tumor occupies thoracic space, pressure inside the SVC increases from 2–8 mm Hg to 20–30 mm Hg, and facial swelling and enlargement of the neck and chest wall become visible. In response to SVC malfunction, the body uses collateral veins located in the thoracic, esophageal, and paraspinal regions—such as the inferior vena cava and the azygos veins—and the patient may experience difficulty breathing or eating. When the collateral veins cannot accommodate the excess pressure, the frequency of the symptoms increases and the patient may die.[5]

Signs and Symptoms

Signs and symptoms of SVCO depend on the acuity and degree of obstruction. The most notable symptoms are swelling of the nose, face, neck, and chest wall, especially in the morning hours after the patient has been recumbent. The swelling gradually subsides, but may remain visible in prolonged cases. Dyspnea—especially when sleeping—hoarseness, constant coughing, lethargy, and head fullness are symptoms of SVCO that may lead to exhaustion. Other clinical signs include facial swelling and abnormally rapid breathing when lying down or bending forward.[6]

Diagnostic Procedures

Physical examination is adequate to diagnose SVCO; however, diagnostic imaging is preferred to provide a more subtle assessment of the patient's condition. Initially, chest radiography is performed to reveal any inflammation or added mass in the right thoracic region, which could be the first sign of SVCO.[3] Computed tomography (CT) scan can reveal the exact location

Box 26.1 Symptoms of Superior Vena Cava Obstruction

- The primary causes of superior vena cava obstruction (SVCO) are lung cancer, lymphomas, thrombus, and stenosis secondary to venous lines.
- Facial and neck swelling commonly present with episodes of shortness of breath.
- Chest x-ray and computed tomography (CT) are used to identify the extent of obstruction, damage, and assist in the development of a treatment plan for SVCO.
- The SVCS grading system and management algorithm are available to guide clinical decisions.

of the blockage, whether it is the result of a thrombosis or tumor, and the extent of cavity damage to determine whether thoracic surgery is necessary.[7]

Magnetic resonance imaging (MRI), often preferred for cancer patients with contrast allergies or renal failure, can show damaged tissue in greater detail and offer different views of the infected area while allowing direct visualization of blood flow to assess pressure inside the SVC. Venography, the most conclusive SVCO diagnostic tool, reveals the full extent of vena cava occlusion and is necessary during preparation for corrective surgery.[8] Contrast venography is the most reliable technique for diagnosis of malignant SVCO; however, if the primary collateral vein—the inferior vena cava—malfunctions due to pressure or tumor necrosis and progresses to venous compression, a radionuclide technetium-99m venography is the preferred alternative.[9]

Treatment

SVC Stenting

SVCO may require endovascular treatments depending on the extent and urgency of the illness. For example, ultrasound-accelerated thrombolysis together with angioplasty and stenting of the SVC can remove a partial or complete obstruction.[10] Venography is essential during stent placement to determine the necessary length and number of stents to open the obstruction.[11] Stent placement has reportedly produced acceptable outcomes in the management of SVCO.[12] A minor complication associated with endovascular intervention is hematoma at the entry site; major complications may include stent migration, bleeding, and pericardial tamponade.[11]

Thrombolytic Therapies

When a thrombus is identified as the cause of mechanical SVCO, thrombolytic therapies are preferred for medical management. The patient may present with acute symptoms of SVCO, warranting delivery of thrombolytic agents via catheter to remove the thrombus.[11] Thrombolytic therapy should be initiated within 2–5 days of the initial symptoms for optimal outcomes and may not be effective if initiated after the 10th day.[11] Tissue plasminogen activator (tPA) is the most commonly used thrombolytic medication.

Drug Therapy

Though lacking evidence-based research to support their effectiveness, short-term administration of anti-inflammatory steroids such as dexamethasone have been used to treat SVCO.[13]

Box 26.2 Superior Vena Cava Obstruction Four-Part Grading System

- Grade: 0–5
- Category: Asymptomatic to Fatal
- Estimated incidence: 10% to <1%
- Definition: Absence of symptoms to death

Source: James BY, Wilson LD, Detterbeck FC. Superior vena cava syndrome—a proposed classification system and algorithm for management. *J Thoracic Oncol*. 2008;3(8):811–4.

Diuretics may also be used despite lack of evidence supporting their effectiveness.[13]

Medical Management

Physicians first work to identify the cause of SVCO, which is most often related to cancer or chronic illness. The care team then works to reduce the symptoms[14]; for example, elevating the patient's head may diminish facial swelling. In SVCO resulting from cancers such as non–small cell lung cancer (NSCLC), the histology of the primary malignant condition is then determined. Radiation therapy may be used when a tumor is the cause of the obstruction. According to Nickloes, chemotherapy is an alternative to radiation therapy for patients with chemotherapy-sensitive tumors.[3]

The increased predominance of SVCO caused by chronic diseases has prompted development of new treatment methods. Endovascular treatment that is effective but less invasive has since become the preferred method for managing SVCO patients in palliative care.[15] The superior vena cava syndrome algorithm developed by Yu, Wilson, and Detterbeck is a useful tool to guide clinical decision-making in the medical management of SVCO patients.[16]

Nursing Management

Nurses should employ palliative techniques to relieve pain and offer comfort to SVCO patients in tandem with medical management. Nursing assessment using the SVCO grading system is essential to identify clinical manifestations of SVCO (see Box 26.2).

It is vital for nurses to build relationships with the patient and their family to reduce stress and improve the patient's functional status. Nurses should also clarify the goals of treatment to ensure they are consistent with the patient's wishes. In addition, nurses should assess the patient's unique coping needs and provide necessary support, ensuring regular therapy tailored for each patient.[17]

Pleural Effusion

Case Study: A Patient with Pleural Effusion

Mr. S, a 39-year-old geologist who worked as an executive with a large oil and gas company, was diagnosed with stage III Hodgkin's lymphoma approximately 4 months ago. He started chemotherapy treatment and completed a positron emission tomography (PET) scan 2 weeks later. While at work last week, he noticed that he was having trouble breathing. The shortness of breath was mild at first, but gradually intensified until he began to sleep in a recliner because he was unable to lay flat at night. Eventually, the shortness of breath became so severe that Mr. S went to the emergency room, where medical personnel detected decreased breath sounds and a chest x-ray confirmed a large PE on the left side.

Description

PE occurs when too much fluid collects in the pleural space. It is commonly known as "water on the lungs" and is characterized by shortness of breath, chest pain, gastric discomfort, and cough. There are two types of pleural effusion: transudative and exudative. A *transudate* is a clear fluid similar to blood serum that forms when the forces that normally produce and remove pleural fluid at the same rate are out of balance, primarily in patients with heart failure. An *exudate* is cloudy fluid containing cells and large amounts of protein that results from disease in the pleura itself. For example, malignancy of the pleura frequently results in malignant PE.[18]

Epidemiology

Parapneumonic disease is the most common cause of PE, followed by malignancy. More than 175,000 individuals in the United States are affected by malignant PE,[19] most commonly secondary to lung cancer. Approximately 15% of lung cancer patients have malignant PE at diagnosis, but 50% of patients with disseminated lung cancer ultimately develop the condition. Breast cancer is the second most frequent cause of malignant PE; however, it is rare among presenting patients but generally occurs with progressive disease. Hematological malignances (lymphomas and leukemia) are the third most frequent cause of malignant PE.[20] The condition, which is generally associated with widespread disease, has a poor clinical prognosis—particularly in patients with malignancy.[21] Most patients with malignant PE are appropriate candidates for hospice care.

Pathophysiology

Each lung is covered with a serous membrane called the *pleura*, forming a closed cavity between the pleura and the lung surface. The normal pleural space contains approximately 10 mL of fluid, representing a balance between (1) hydrostatic and oncotic forces in the visceral and parietal pleural capillaries and (2) persistent sulcal lymphatic drainage. Osmotic and hydrostatic pressures act to maintain equilibrium between absorption and production of fluid in the pleural space. When this equilibrium is disturbed, fluid can accumulate in the pleural cavity.[22]

Pulmonary effusion is attributed to altered permeability of the pleural membranes caused by multiple conditions including inflammation, malignancy, and pulmonary embolism. In patients with malignancies, it is not uncommon to have multiple simultaneous causes of PE. Hypoalbuminemia can reduce intravascular oncotic pressure and increased capillary permeability, or vascular disruption can result from trauma, malignancy, inflammation, infection, or pulmonary infarction.[22]

Signs and Symptoms

Dyspnea, which may develop suddenly or gradually depending upon on how rapidly the fluid accumulates, is the most common symptom of PE and often results in increased anxiety. If the effusion is free-flowing, dyspnea will become more severe while the patient is fully prone; however, shortness of breath will remain constant regardless of the patient's position if the effusion is loculated. A large effusion will cause sudden and severe shortness of breath, whereas onset is more gradual with a small and slowly developing effusion. Patients may experience pleural pain, an intense pain in the chest area that is sometimes confused with cardiac pain.

The patient's inability to expand the lung leads initially to reports of exertional dyspnea. As the effusion volume increases, resting dyspnea, orthopnea, and tachypnea develop. The patient may describe a dry, nonproductive cough and a heaviness or aching pain—often described as dull or pleuritic—in the chest. Physical examination commonly reveals increased respiratory rate and use of accessory muscles for breathing. Auscultation indicates decreased breath sounds on the affected side, and percussion shows dullness in the affected lung field. A large effusion may cause tracheal deviation and mediastinal shift to the affected side.

Diagnostic Procedures

Chest X-ray

Standard anteroposterior and lateral chest radiography remain the most important techniques for initial diagnosis of PE. A fluid volume of 200 mL will be evident on a anteroposterior film, and costophrenic angle blunting can be seen on a lateral film at an accumulation of only 50 mL.[23] A chest x-ray will reveal whether the fluid is free flowing versus loculated, which will determine the preferred treatment plan.

Ultrasound

Ultrasonography can accurately detect even small amounts of PE, as characterized by an echo-free space between the visceral and parietal pleura. Ultrasonography is used to confirm a diagnosis of loculated PE and in marking a site for thoracentesis.[23]

Computed Tomography Scanning

CT scanning produces cross-sectional images that are useful for evaluation of complex cases where routine radiography or ultrasonography cannot provide a conclusive assessment. CT scanning can show pleural or lung masses, adenopathy, pulmonary abnormalities such as infiltrates or atelectasis, or distant disease.

Thoracentesis

Thoracentesis is indicated for all patients with more than a minimal PE (i.e., >1 cm in height on lateral decubitus radiography, ultrasonography, or CT scanning) of unknown origin. In some cases, once evidence of the effusion has been established and obvious nonmalignant causes have been ruled out, thoracentesis may be helpful in confirming the diagnosis.[23] Sonographic guidance can prevent problems associated with performing "blind" thoracentesis.

Treatment

Medical management of malignant PE depends on multiple factors, including the history of the primary tumor, prior patient history and response to therapy, extent of disease and overall medical condition, goals of care, and severity of symptom distress. It is important to evaluate the underlying cause of the PE and determine whether it can be treated to prevent further accumulation of fluid. This treatment might include systemic therapy (e.g., chemotherapy, antibiotics), hormonal therapy, or radiation therapy. Symptomatic management includes the use of opioids to manage pain and dyspnea, as well as anxiolytics to control concomitant anxiety. The most common treatments for PE include (1) observation to see how it responds to treatment of the underlying disease, (2) thoracentesis, (3) pleurodesis, (4) indwelling pleura catheter placement, and (5) palliation of symptoms.[24]

Thoracentesis

Thoracentesis has been shown to relieve dyspnea associated with large PEs. Although thoracentesis may produce rapid relief of symptoms, fluid reaccumulates quickly—usually within 3–4 days—and within 30 days in 97% of patients.[25] When fluid reaccumulates, it must be decided whether the risks of repeated thoracentesis outweigh the benefit. Risks include empyema, pneumothorax, unexpandable lung from inadequate drainage and/or loculated fluid, and possible increasing tissue malnutrition from the removal of the protein-rich effusion fluid. If the risks outweigh the benefit, alternative treatments including pleurodesis, pleurectomy, or indwelling catheter must be considered.

Pleurodesis

Pleurodesis is not recommended in patients who have a life expectancy of less than 3 months.[26] Palliative treatment, especially for those with a life expectancy of months rather than weeks, is best accomplished by thoracentesis or pleural catheter placement. The goal of pleurodesis is to drain the pleural cavity completely, expand the lung fully, and instill a chemical agent into the pleural cavity. With a large effusion, only 1,000–1,500 mL should be drained initially to avoid reexpansion pulmonary edema from rapid draining of large volumes, as in some cases large hydropneumothorax has resulted from rapid evacuation of large PE fluid volumes.[21]

After placement, the chest tube is connected to a closed-drainage device. To prevent reexpansion pulmonary edema, water-seal drainage and intermittent tube clamping should be used to allow fluid to drain slowly. Complications of chest tube placement include bleeding and development of pneumothorax, which results from rapid fluid removal in patients with an underlying noncompliant lung. The procedure causes pain and requires aggressive pain management with opioids and possible sedation.

The purpose of pleurodesis is to administer agents that cause inflammation and subsequent fibrosis into the pleural cavity to produce long-term adhesion of the visceral and parietal pleural surfaces to prevent reaccumulation of pleural fluid. Sclerosing agents or chemical irritants used to treat malignant PE include talc, tetracycline, minocycline, doxycycline, silver nitrate, bleomycin, cisplatin, recombinant adenoviral human p53, and human tumor necrosis factor (see Table 26.1).[27–29]

Table 26.1 Agents used to treat malignant plural effusion

Agent	Characteristics
Talc	Trilayered, magnesium sheet silicate Most effective and most commonly used
Minocycline and Doxycycline	Tetracycline derivatives Less effective than talc
Silver nitrate	Tetracycline derivatives Equal effectiveness to talc
Bleomycin	Less commonly used because of systemic toxicity and cost
Cisplatin	Widely used in patients with lung cancer
Recombinant adenoviral human p53 (rAD-p53)	Higher short-term response rate and fewer side effects than cisplatin Less effective but fewer side effects than talc

Pleurectomy

Pleurectomy, a surgical stripping of the parietal pleura, is a possible treatment for malignant pleura effusion, but this surgery lacks evidence as treatment in comparison to pluerodesis.[21] Video-assisted thoracoscopy (VATS) and pleurectomy have been performed successfully, but this intervention is generally inappropriate for the palliative care patient at end of life.

Indwelling Pleural Catheters

Patients with symptomatic, unilateral effusions who have a reasonable performance status may benefit from indwelling pleural catheters, which can be placed under local anesthesia. It has been suggested that tunneled pleural catheters may provide better long-term drainage and symptom control of malignant PE.[21] The tunneled catheter is a small-bore tube attached to a gravity drainage bag or vacuum drainage. Most patients and families can be taught to drain the effusion effectively with few side effects. Rare complications include tumor seeding, obstruction, infection, cellulitis of the tract site, and pain during drainage. This treatment offers the potential for better quality of life (QOL) and reduction of overall health care costs.[30]

Nursing Management

Nursing management includes symptom control, education, and communication regarding goals of care. Symptoms most commonly associated with PE are dyspnea, pain, and anxiety, which are treated aggressively with medications, education, and nonpharmacological techniques. Nurses should educate patients and their families about each procedure, including its purpose, how it is carried out, how pain will be addressed, home care techniques, and possible side effects or complications. A variety of nonpharmacological techniques can be used to relieve dyspnea and pain, including comfortably positioning the patient, using relaxation techniques, and providing oxygenation as appropriate.

Education is a large component of the nursing role in managing patients with PE, including instruction on treatment options and on self-management of interventions. For example, if the patient has a tunnelled catheter the family must recognize the importance of monitoring drainage volume to detect possible spontaneous pleurodesis, which can be identified through increased drainage output over time. Because PE and its associated symptoms are distressing to patients and family members, nurses should encourage open communication about their distress, concerns about advancing disease, and goals of care.

Hemoptysis

Case Study: A Patient with Hemoptysis

Ms. C, a 60-year-old retired waitress, was diagnosed with small-cell lung cancer 3 months ago. Initially hesitant to pursue treatment, she consulted with her family and decided to seek chemotherapy and radiation therapy. While at the clinic for treatment, Ms. C told the oncology nurse that she was concerned because she had been coughing up blood 3–4 days per week for about 2 weeks.

Hemoptysis, or expectoration of blood, can present in a broad range of conditions and manifestations.[31] The blood can range from small streaks in the sputum from the lungs to a larger volume of blood without any sputum. Hemoptysis can also result from bleeding outside the lungs and the airways.[31] Blood-tinged sputum mixed with blood suggests lung disease; *pseudohemoptysis* is coughing up blood that does not originate from the lungs.[32]

Epidemiology

According to research by the American College of Chest Physicians involving patients hospitalized for various diseases, lung cancer was the leading cause of hemoptysis at 40.6%. Bronchitis, tuberculosis, and pneumonia are the other significant causes of hemoptysis at 25%, 17%, and 10% respectively.[33]

Blood volume loss from hemoptysis can be minimal to massive or even life-threatening. While literature is inconsistent regarding volumes of massive hemoptysis, studies identify different volume thresholds ranging from 100 to 1,000 mL over a 24-hour period. Because of this inconsistency, it is recommended to measure blood loss on admission.[34] Mortality risk among patients with massive hemoptysis is greater than 80% without a timely intervention.[34]

Pathophysiology

The pulmonary and bronchial arteries are the two systems of blood supply in the lungs. The pulmonary artery facilitates gas exchange at low pressure, while the bronchial arteries are part of the systemic blood circulation at much higher pressure. The high pressure is partly responsible for the bronchial arteries being the primary source of hemoptysis, although nonbronchial arteries also contribute to the condition. When an infection such as bronchitis increases pulmonary circulation, the increased pressure results in bursting of the thin walls, causing overflow of blood into the alveoli and bronchi leading to hemoptysis. Similarly, chronic illnesses such as lung cancer can cause blood overflow when a growing tumor or the spread of malignant cells promotes the growth of fragile collateral vessels or the remodeling of other arteries. Lung cancer patients account for 7–10% of hemoptysis cases.[35] The blood vessels are thin-walled and prone to bursting from the slightest provocation, such as an acute case of vomiting. The bronchial arteries account for 90% of bleeding instances, while the pulmonary artery causes only 5% of cases.[36] The remaining episodes result from the nonbronchial systemic arteries. When blood overflows, it searches for an opening, which accounts for blood in the sputum when coughing or when vomiting.

Diagnostic Procedure

The source of the bleeding causing the hemoptysis must be quickly identified. A medical history and physical examination are completed to collect subjective and objective information that will assist in differentiating whether the patient has hemoptysis, hematemesis, or pseudohemoptysis. Diagnostic testing begins with a lateral chest x-ray; however, x-rays can offer insufficient information and a chest multiple detector CT (MDCT) may be ordered for patients with blood-streaked sputum and chronic illness such as lung cancer.[37] The MDCT locates the source of the bleeding and indicates the exact presence, number, origin, and trajectory of the bronchial and pulmonary arteries that may be the source of bleeding. The MDCT can detect 70–88% of cases resulting from bronchial artery overflow and 62–97% of the nonbronchial arteries that cause bleeding.[35] The MDCT may be followed by a diagnostic bronchoscopy, which is carried out during active hemoptysis or within 24–48 hours after cessation and can detect the source of bleeding in 73–93% of cases.[35]

Signs and Symptoms

The signs and symptoms of hemoptysis are specific to the area of possible involvement. It is difficult to predict the severity and course of hemoptysis,[32] therefore careful assessment is key. Cardiac signs and symptoms include tachycardia, heart murmur, chest pains, and fixed split S2. Respiratory signs and symptoms include tachypnea, voice hoarseness, wheezing, pursed lip breathing, decreased lung sounds, and shortness of breath.[38] The patient may also present with fever, cachexia, or nausea.

Differential diagnoses are formulated based on assessment findings. For example, findings for bronchogenic tumors may include night sweats, weight loss, and history of heavy smoking. Findings significant to pneumonia are fever, productive cough, decreased breath sounds, and pleuritic chest pain.[38] Because the causes for hemoptysis can be unclear, a thorough and accurate assessment is essential to identify the cause and location of the bleeding.

Management

There are two types of hemoptysis: nonmassive and massive. Common goals for the management of either type are to (1) identify the origin of bleeding, (2) stop the bleeding, (3) treat the underlying cause, and (4) prevent aspiration in patients with massive hemoptysis.[38]

Nonmassive Hemoptysis

The treatment plan for patients with nonmassive hemoptysis is focused on the cause of the bleeding and the blood volume loss over 24 hours. The blood volume should be scant or minimal, as this suggests a self-limiting cause such as pneumonia. This patient will require a standard chest x-ray for diagnosis confirmation and is considered low risk. Treatment is managed in the outpatient setting and involves a normal follow-up appointment. Some patients' hemoptysis may be high risk and require an outpatient CT. Nursing management of nonmassive hemoptysis includes establishing patient trust, education, and emotional support.

Massive Hemoptysis

Medical management for the patient with massive hemoptysis begins with airway protection and establishment of hemodynamic stability. Any acquired coagulopathies such as thrombocytopenia, disseminated intravascular coagulation, or drug-induced platelet dysfunctions are then identified and treated.[34] Hemoptysis has proved to be a difficult and uncertain symptom to manage, but recent technological advances and newer and better techniques (see Table 26.2)—such as bronchial artery embolization—have facilitated more effective symptom management.[33]

Nursing Management

The patient with massive hemoptysis, which can result in death if not resolved immediately, requires emergent management. Nursing management begins with a respiratory assessment to identify patients at risk for a compromised airway or aspiration.[33] Vital signs are monitored for significant hemodynamic changes because massive blood loss can lead to sudden cardiovascular instability. This situation can be frightening for the patient as well as the family, therefore the nurse should provide emotional support if needed. When hemoptysis occurs at end of life in people with cancer, aggressive therapies such as endoscopy, embolization, or surgery are used depending on the patient's condition, the likelihood of success based on the diagnosis, and the patient's goals of care.[35]

Table 26.2 Common treatments for hemoptysis

Procedure	Characteristics
Bronchial artery embolization (BAE)	Preferred due to its effectiveness and reduced invasiveness Stabilizes pressure and reduces risk of bleeding
Endoscopic treatment	Used to locate and identify the cause of bleeding in the lungs Airway patency is paramount and requires preparation for emergent interventions
Cold saline lavage	Used to control bleeding and improve visualization during a bronchoscopy Effectiveness has not been established
Endobronchial stents	Used to treat stenosis or obstruction of the bronchus Palliative treatment for respiratory distress
Laser photocoagulation (Nd: Yag laser)	Used to decrease hemoptysis in patients with central airway tumors Several lasers of different wavelengths available
Pulmonary isolation	Used to prevent blood from severe hemoptysis from entering unaffected lung Accomplished by selective endo-bronchial intubation (SEI) or placement of a bronchial blocker
Selective endobronchial intubation	Placement of an endotracheal tube opposite the bleeding site Must not occlude the wrong side in the bronchus
Bronchial blocker	Placed through an endotracheal tube to isolate bleeding site Can be repositioned as needed to explore other possible bleeding sites

Spinal Cord Compression

Case Study: A Patient with Spinal Cord Compression

Mrs. S is a 54-year-old woman who was diagnosed with breast cancer 3 years ago and was treated with a resection followed by radiation therapy. On a recent visit with her oncologist, she complained of significant back pain and said that she can't enjoy her grandkids anymore. Mrs. S thought her back was giving out, but was informed 2 months ago that cancer was found in her spine.

Description

SCC is a medical emergency in which the spinal cord is compressed as a result of pressure, for example from a bone fragment or tumor. SCC can occur anywhere between the cervical and the lumbar regions as a result of wear and tear on the vertebrae, spinal tumor, injury to the spine, bone disease, or infection.[39] The condition occurs in 5–10% of patients with advanced cancer. Rates of occurrence for different cancers are breast malignancies (5.5%), prostate cancer (7.2%), myeloma (7.9%) and nasopharynx (6.5%).[40] This condition qualifies as an end-of-life (EOL) manifestation because of its incidence in patients with terminal illness.

Pathophysiology

The pathophysiology of SCC includes injury as a result of trauma, infection, or inflammatory disease; however, tumors are the primary cause. At the point of epidural intrusion, venous flow in the spine is affected and the patient may experience sharp irregular pains during activities like walking. As the spread of malignant cells infiltrates the white and gray matter, and, depending on the level of the terminal illness, the patient experiences tissue death.[40] When the malignancy enters the bony structures of the vertebrae, the cells spread to the bones that support the arms and patients often experience difficulties walking and maintaining a straight posture. The pelvis, femur, ribs, humerus, and the skull are systematically destroyed, significantly impacting motor abilities and causing loss of bowel, bladder, and sexual function, followed by paralysis.[41]

Diagnostic Procedures

Diagnostic imaging used to identify spinal cord injuries includes spinal x-ray (usually insufficiently sensitive), CT scan, and gadolinium-enhanced MRI, which is the gold standard for its specificity and sensitivity.[41] MRI of the complete spine is useful because tumors are found at multiple sites along the spine in one-third of patients.[42]

Signs and Symptoms

Symptoms of SCC depend on the affected region of the spinal cord; however, back pain is the first sign of the condition in most cases.[43] The pain worsens with specific activities such as coughing, sneezing, or straining while toileting and can lead to difficulties during walking. Other non–pain-related symptoms include loss of bladder control, weak limbs, erection problems, and changes to body sensations.

Signs of SCC occur in four stages starting with pain and weakness and ending with ataxia and sensory loss. Back and neck pain, the earliest and lowest level symptoms, are the most common signs of SCC. Ataxia and loss of sensation are the highest level symptoms and are a critical EOL manifestation. Patients with ataxia have abnormal gait and nervous system dysfunction such that the person cannot coordinate body movements.[44] During ataxia, the patient cannot receive any treatment, and nurses manage the condition by providing hospice care. In the final stage of the illness before death, symptoms worsen and compression blocks nerve impulses, leading to paralysis and complete loss of sensation.[44] Hospice management of SCC symptoms at end of life depends on the patient's pain level and the stage of the condition.[45]

Metastatic SCC (MSCC) warrants intervention as early as possible. These signs and symptoms of MSCC would trigger a referral within 24 hours: (1) pain in the thoracic area, (2) spinal pain aggravated by straining, (3) localized spinal tenderness, and (4) nocturnal pain preventing sleep.[46] Emergent signs and symptoms that warrant an immediate referral in oncology patients are (1) loss of coordination, (2) bladder or bowel dysfunction, and (3) limb weakness and inability to walk.[46]

Medical and Nursing Management

Patients with SCC require consistent pain and neurological assessments to manage pain effectively and prevent additional neurological deficits that could diminish QOL. Important aspects of medical management topics for the SCC patient are analgesia, corticosteroids, radiation therapy, and decompression surgery.

Analgesia

The SCC patient will at some point experience discomfort and back pain as the spinal cord becomes more compressed.[42] Consequently, continuous pain assessment and management are essential. Several modalities can be used to effectively manage pain, including opioid and nonopioid analgesics and nonpharmacologic techniques. For cases of severe pain in patients with spinal tumors, opioids are the first-line medications to effectively manage pain.[47] When opioids are prescribed, the patient should be placed on a bowel regimen to prevent constipation and prevent any additional triggers of pain by straining. If pain is decreased and managed, opioids should be titrated accordingly.

Corticosteroids

Corticosteroids are essential to reducing edema at the compressed site in patients with SCC, and particularly in patients with MSCC, so that optimal radiation therapy can be applied at the tumor site.[42] As the edema around the spinal cord is reduced, compression pain may decrease and neurological function may improve.[47] Corticosteroids have adverse effects that must be monitored during steroid therapy, including weight gain, fluid retention, increased appetite, and facial puffiness.

Radiation Therapy

Radiation therapy is used to decrease the size of a tumor that is compressing the spinal cord, especially in cases of radiosensitive tumors.[42] Radiation treatment is guided by tumor size, spine stability, and the degree of symptoms related to the spinal cord compression.[41] Radiation therapy may be for palliative reasons if the patient has 6 months or less to live, but the National Institute of Health and Care (NICE) recommends single fraction radiation therapy.[48] Patients receiving radiation therapy may encounter side effects specific to the site of therapy, but general symptoms include fatigue, alopecia, nausea, and pain.

Decompression Surgery

Spinal surgery is required to remove a tumor compressing the spinal cord. Spinal surgery for patients with SCC would be the optimal choice if there is spinal instability, but spinal tumor patients with a prognosis of 2–3 months will receive palliative radiation therapy in lieu of surgery.[41]

In the management of SCC, regular exercise strengthens body muscles and keeps the spine flexible. Furthermore, maintaining proper body posture when standing, sitting, and sleeping maintains the natural body and spinal curve to avoid strain. In addition, a reasonable body mass index reduces extra pressure on the spine and minimizes the risk of spinal damage. The administration of body mechanics such as exercise routines, massages, and hot showers can be used to reduce back pains.

Hypercalcemia

Case Study: A Patient with Hypercalcemia

Mr. C is a 54-year-old tree cutter recently diagnosed with metastatic lung cancer. He was in good health until approximately 6 weeks ago when he noticed shortness of breath and fatigue. His primary care doctor treated him for bronchitis, but his doctor ordered a chest x-ray when he did not respond to treatment. The chest X-ray showed a lung mass with enlarged mediastinal lymph nodes. Diagnosis was confirmed by outpatient biopsy and an oncology appointment was scheduled. Unfortunately, he was admitted to a local emergency room with altered mental status and lethargy before his appointment and was found to have hypercalcemia with ionized calcium.

Description

Hypercalcemia is an excessive amount of ionized calcium in the blood. Patients with a corrected serum calcium level less than 12 mg/dL are considered to have mild hypercalcemia, those with serum calcium levels of 12–14 mg/dL are classified as having moderate hypercalcemia, and those with a calcium level greater than 14 mg/dL are classified as severe.

It is most frequently associated with multiple myelomas and breast cancers, but is also observed in patients with squamous cell carcinomas of the head and neck, lung, kidney, and cervix. It is much less common in patients with prostate cancer, small-cell lung cancer, and gastric/large bowel tumors.[49] Incidence ranges from 30% to 40% in breast cancer patients with bone metastases, 20% to 40% in patients with multiple myeloma, 12.5% to 35% in those with squamous cell lung carcinomas, and 2.9% to 25% in patients with head and neck malignancies.[49]

Primary hyperparathyroidism and cancer account for around 90% of hypercalcemia cases. Primary hyperparathyroidism occurs in around 25 people per 100,000 in the general population. Most episodes of malignancy-associated hypercalcemia occur in patients with advanced disease and typically result in a poor prognosis with 30-day mortality in up to 50% of patients.[50]

Pathophysiology

Hypercalcemia in malignant disease is primarily due to increased mobilization of calcium from bone, although increased renal tubular calcium resorption is also a factor. The most common cause (80%) is humoral hypercalcemia of malignancy (HHM). Parathyroid hormone-related protein (PTHrp) released into systemic circulation by cancer cells is the primary mediator. PTHrP shares significant N-terminal homology with parathyroid hormone (PTH) and stimulates osteoclastic bone resorption and renal tubal calcium reabsorption. In addition to hypercalcemia, PTHrP is important in other aspects of cancer biology including susceptibility and tumor behavior.[51] Twenty percent of cases are due to local osteolytic hypercalcemia (LOH) associated with multiple myeloma and metastatic cancers with large bone burden (e.g., breast, lung). Calcium is mobilized by osteoclasts activated by paracrine products.[52] Both HHM and LOH involve proliferation and activation of osteoclasts that resorb bone and generate hypercalcemia. Activation of vitamin D (seen with lymphomas) and secretion of native PTH are less common causes of hypercalcemia.

The kidneys normally adapt to disturbances in calcium homeostasis. However, in the presence of malignancy, patients may experience treatment or disease-related side effects including vomiting, mucositis, anorexia, dysphagia, and fever—all of which can lead to volume depletion. This imbalance signals the kidneys to resorb sodium to correct extracellular volume depletion. Calcium and sodium resorption is closely linked in the body; when sodium is resorbed, calcium follows. As calcium ions are resorbed in the kidney, the tubules lose their ability to concentrate urine, leading to high-output polyuria and further dehydration. Poor renal perfusion reduces glomerular filtration and compromises excretion of calcium, leading to a further increase of calcium in the blood and eventual renal failure.

High calcium level can significantly alter a patient's mental status, which in turn can greatly affect the patient's ability to drink fluids. Cellular dehydration and resulting hypotension are exacerbated by decreased proximal renal tubule reabsorption of sodium, magnesium, and potassium. Bone loss due to immobilization, lack of physical exercise, inappropriate use of thiazide diuretics, poor diet, and general physiological wasting will also increase the amount of free calcium ions in the circulation, further increasing calcium levels.

Symptoms of hypercalcemia are easily overlooked as they are insidious and nonspecific. Symptoms, their severity, and how quickly they appear vary from patient to patient. Mild symptoms of hypercalcemia include fatigue/lethargy, mental dullness, weakness, anorexia, increased thirst, polyuria, and constipation. Severe symptoms include drowsiness, delirium, nausea, vomiting, confusion, dehydration, and coma.[49] The most common symptoms are gastrointestinal, including nausea, vomiting, anorexia, constipation, and, in extreme cases, ileus. Polyuria and polydipsia are associated with hypercalcemia due to impaired renal tubular concentration.[52] Bone pain can be caused by cancer, but may also be a symptom of hypercalcemia. Rare symptoms include bradycardia and shortening of the QTc interval, wide T waves, cardiac arrhythmias, and prolonged PR interval.[49]

Because the symptoms of hypercalcemia can mimic both side effects of cancer treatment and progression of the disease, a thorough assessment is essential to the diagnosis and treatment of hypercalcemia. Many symptoms of hypercalcemia cause the patient to become increasingly dehydrated, which increases the hypercalcemia and creates a spiraling effect.

Ionized calcium concentration is the most important laboratory test in the diagnosis of hypercalcemia and the most accurate indicator of the blood calcium level, although the correlation between total serum calcium level and ionized calcium is fair at best. When ionized calcium cannot be used as a diagnostic tool, total serum calcium value may be used but must be corrected for serum albumin.[53] The formula is:

$$\text{Corrected Total Ca}^{2+}\text{mg/dL} = \text{Total measured calcium (mg/dL)} + 0.8\ (4\text{-measured albumin [g/dL]})$$

Treatment

Regardless of the overall goals of care, the active treatment goal for hypercalcemia is to alleviate distressing symptoms. Trial of therapy is warranted in all patients with symptomatic hypercalcemia, if the treatment will not exacerbate their existing symptoms. Hypercalcemia is reversed by replenishing depleted intravascular volume, promoting diuresis of calcium, shutting down osteoclast activity in the bone, inhibiting renal tubular reabsorption of calcium, and promoting patient mobilization to the greatest extent possible.[54] Table 26.3 lists commonly used treatments for hypercalcemia.

Hydration is the first step in effective treatment. Although restoration of fluid volume will aid in diluting the serum calcium concentration, its primary purpose is to increase calcium excretion. Electrolytes and other laboratory values are closely monitored including serum calcium (ionized or corrected), potassium, magnesium, other electrolytes, albumin, and bicarbonate levels. Renal function tests, including blood urea nitrogen (BUN) and creatinine, are also monitored, and dialysis may be considered in rare cases. In most patients, cardiac effects of hypercalcemia are minimal and outcomes are not usually affected, so cardiac monitoring is unnecessary.

Table 26.3 Common Treatments For Hypercalcemia In Palliative Care

Treatment	Mechanism of action
Hydration with IV fluids	Increase urinary calcium excretion & improve kidney function
Bisphosphonates (pamidronate and zoledronate most frequently)	Inhibit osteoclast activity
Denosumab	Monoclonal antibody leading to inhibition of osteoclast differentiation and bone resorption
Calcitonin	Inhibits calcium resorption
Dialysis	Dialyze excess calcium out

Bisphosphonate Therapy

After fluid administration, the first-line treatment option for malignant hypercalcemia is intravenous bisphosphonate therapy, an effective therapy for a number of cancers.[55] Bisphosphonates have a high affinity for the mineral component of bone, which allows them to reach very high skeletal concentrations.[53] Three bisphosphonates are currently available in intravenous form (bioavailability 1–2%), but only pamidronate and zoledronate are approved by the US Food and Drug Administration (FDA) for the treatment of malignancy-associated hypercalcemia.

Pamidronate has been the most frequently used bisphosphonate, but zoledronate is becoming more widely used in the outpatient setting due to its much more rapid infusion time. Pamidronate is usually given as 90 mg intravenously over 2 hours and has a response rate of 33.3% within 4 days, 63.6% within 7 days, and complete response within 18 days. Zoledronate is usually administered as 4 mg intravenously over 15 minutes and has a 45.3% response rate by day 4, an 82.6% response rate by day 7, and a complete response within 32 days.[54] Pamidronate and zoledronate can cause renal toxicity, making evaluation and continued monitoring of kidney function essential before and during administration. Some clinicians may opt to use pamidronate in lower doses over longer durations for renal patients. Bisphosphonates can cause osteonecrosis of the jaw, especially in patients with myeloma who have been treated with pamidronate and zoledronate over a long period of time and those with dental problems.[56] Since hypercalcemia tends to recur, pamidronate or zoledronate must be administered approximately every 4 weeks.

Immediate side effects of pamidronate therapy include low-grade fever appearing within 48 hours of treatment and redness, induration, and swelling at the catheter site. Hypomagnesemia and hypocalcemia may also occur. Rapid administration of intravenous bisphosphonates can cause significant pain and should be avoided. Subcutaneous administration of clodronate has been found to be an efficient treatment for malignant hypercalcemia[56] and may be particularly useful in hospital, home, and hospice settings. This approach reduces patient discomfort and decreases costs associated with transportation and intravenous administration in the hospital environment.

It is important to evaluate the entire clinical picture when choosing a bisphosphonate. Hydration is crucial before using this medication. Careful assessment of the severity of hypercalcemia, fluid volume status, renal function, and disease status should guide which type of bisphosphonate is used. Another consideration is the significantly lower cost of pamidronate compared with zoledronate (average wholesale price of $104 vs. $713, respectively).[48] However, pamidronate may result in longer hospitalizations, resulting in a similar overall cost of treatment.

Calcitonin

Calcitonin inhibits calcium resorption and can rapidly restore normal calcium, often within 2–4 hours of administration; however, it is much less effective than pamidronate. Its role in managing hypercalcemia is limited to short-term use of 2–3 days. Side effects are usually mild and may include nausea and vomiting, skin rashes, and flushing. Calcitonin can be an alternative treatment in patients with kidney failure for whom pamidronate and zoledronate are contraindicated.[56]

Denosumab

Denosumab is a monoclonal antibody that may also be a treatment option for patients with hypercalcemia of malignancy. Limited research suggests that this medication could benefit patients who cannot receive bisphosphates because of renal failure.[57] Denosumab was approved by the FDA in late 2014 for treatment of malignancy-associated hypercalcemia refractory to bisphosphonates based on an open-label, single-arm study of patients diagnosed with malignancy-associated hypercalcemia who were unresponsive to bisphosphonate therapy.[58] However, monoclonal antibodies are extremely costly and logistics often make them a less than ideal treatment option for emergency management of malignant hypercalcemia.

Dialysis

Removal of calcium by hemodialysis against a low-calcium dialysate bath and continuous renal replacement therapy using citrate as an anticoagulant and a calcium chelator has been reported.[52]

Nursing Management

Hypercalcemia can cause distressing symptoms including bone pain, agitation and confusion, severe constipation, and delirium. Treatment can reduce pain and other symptoms, improve QOL, and reduce hospitalizations. At end of life, promotion of comfort and symptom management are the primary goals of palliative nursing care. If hypercalcemia cannot be reversed or if the patient decides that the burden of interventions is greater than the benefit, the patient should be offered the option to discontinue treatment.

Hypercalcemia is a life-threatening condition that frequently occurs in end-stage cancer patients. Nurses must be well-versed in the treatment options for hypercalcemia and be able to clearly explain the advantages and disadvantages of each treatment to assist patients and their families in making educated choices. Because hypercalcemia is very symptomatic, it is also important for the nurse to review the symptom management plan with the patient and family. If the patient and/or family decide to withdraw or withhold treatment for hypercalcemia, it is the nurse's responsibility to support them in their decision. Ongoing education is essential to support the patient and family, as the patient will eventually die from untreated hypercalcemia.

Bone Metastasis and Pathological Fractures

Case Study: A Patient with Pathological Fracture

Ms. W. is a 61-year-old woman who had been receiving treatment for multiple myeloma; however, her treatment was put on hold when her insurance was terminated. Although she was working with the palliative care social worker to re-establish her insurance, she was temporarily without systemic treatment. While sweeping her patio, Mrs. W. had a sudden onset of severe pain in her upper left arm. After talking with the palliative care team by phone, she was instructed to report to the outpatient clinic. On arrival, she described severe pain in her upper arm with swelling, bruising, and loss of function.

Description

A pathologic fracture is a bone fracture resulting from weakness of the bone structure caused by disease. This process is most commonly due to osteoporosis, but may also be caused by other pathologies such as cancer, infection (such as osteomyelitis), inherited bone disorders, or a bone cyst.

Epidemiology

Metastatic disease is the most common bone malignancy, with prostate, breast, lung, kidney and thyroid cancer accounting for 80% of skeletal metastases.[59] The most common sites of bone metastases are the spine, pelvis, ribs, skull, and proximal femur.[59] It has been reported that 9–29% of patients who suffer from bone metastases develop pathological fractures,[60] most commonly in the long bones, although the spine is the most common site of skeletal metastases.

There is a 3-year survival rate of patients with bone metastases and pathological fractures as compared to those without pathological fractures (19% vs. 35%).[60] The most commonly reported survival rates across all patients are in the range of only 30–40% at 1 year. Median time from fracture to death across all patients was only 3.3 months, although the actual times were affected by the type of cancer and Eastern Cooperative Oncology Group (ECOG) score. Breast cancers had the best outcomes, with median survival time of 6.3 months, prostate cancer had a median survival time of 4.5 months, and lung cancer fared the worst with a median time of only 2.4 months from fracture to death.[60]

Pathophysiology

Once in the marrow, metastatic cancer cells take advantage of normal marrow physiology to survive away from the primary tumor.[61] Bone marrow is a unique environment that houses both cells of hematopoietic lineage and cells responsible for bone remodeling (osteoblasts and osteoclasts). These disseminated tumor cells (DTCs) also actively influence bone remodeling to create a favorable environment for further recruitment and better survival of DTCs within the marrow.[62] Subsequently, DTCs become dormant and eventually regrow.

Pain is usually the first sign of bone metastasis and is usually worse at night and may improve with movement. As the bone metastasis progresses, the pain becomes more severe and worsens with activity. Continued weakening of the bone because of the metastasis could eventually lead to a pathological fracture. Signs of pathological fracture are sudden onset of pain in the affected area, in addition to possible swelling, bruising, and loss of function.

Pathological spinal fractures usually cause severe pain or progressive neurological deficits; hence, prevention of pathological fractures is a primary goal in the management of spinal metastasis. However, diagnosis of spinal metastasis is frequently delayed because the onset of symptoms often results from neural tumor invasion or development of pathological fracture, which is initial manifestation of spinal metastasis in many cases.[63] Hypercalcemia may also result from bone metastasis, causing symptoms that include constipation, nausea, loss of appetite, extreme thirst, fatigue, weakness, sleepiness, and confusion. The high calcium also causes more urine output, leading to dehydration.

Diagnostic Procedures

Bone metastases are sometimes diagnosed when the patient seeks care because of pain or other symptoms. They are also sometimes found during the initial cancer workup or during follow-up imaging to determine response to treatment. In either case, bone metastases are usually found on an x-ray, a bone scan, a CT scan, an MRI, or a PET scan.

In osteolytic or lytic metastases, the cancer cells dissolve the bone making part of it less dense. If the cancer has destroyed enough of the bone, these changes look like a darker hole in the gray-white bone seen on an x-ray. Osteoblastic or blastic metastases cause an area of the bone to look denser or sclerotic, which appears on x-rays as spots that are whiter than the bone around them. Bone metastases often have both lytic and blastic features.

Occasionally, a blood and/or urine test will be ordered to evaluate for the presence of substances that indicate bone metastasis. A blood test, for example, may reveal high calcium and/or elevated alkaline phosphate. Several substances can be released into the urine when bone is damaged, such as N-telopeptide. Bone metastasis is confirmed through biopsy, frequently guided by CT scan.

Treatment

The goals of treatment for bone metastasis and pathological fractures are to relieve pain and restore function without causing further decline in QOL. Management options for skeletal metastases vary with bone type, anatomical location, and loading condition.[59] Treatments include radiation therapy, systemic treatment, embolization, electrochemotherapy, radiofrequency ablation (RFA), and high-intensity focused ultrasound (HIFU).[59] Treatment of pathological fractures involves surgery and splinting or immobilization.

Bone Metastasis Treatment

Palliative radiation. Palliative radiation therapy can reduce pain in 60% of patients, with about 25% of patients achieving complete response.[63] Palliative radiation therapy can be administered as conventional external-beam radiation or intravenous bone-seeking radiopharmaceuticals. The goals of palliative radiation therapy are to use a short treatment schedule to minimize the commitment of time for therapy and to achieve rapid symptomatic relief.[59] No significant difference in pain relief has been reported between single and multiple fractions of radiation therapy.[62] Palliative radiation is associated with few side effects, but an increase in bone pain called a "pain flare" occurs immediately after radiation therapy in 2–44% of cases.[63] Bone-seeking radiopharmaceuticals, such as radium-223 (^{223}Ra), selectively deliver ionized radiation to target areas of amplified osteoblastic activity.[64]

Systemic treatment. Palliative chemotherapy that is targeted to the treatment of a specific cancer can be used to treat bone metastasis; however, cancer metastasis remains poorly understood in terms of clinical outcome, pathology, and tissue specificity of different tumor types. The predilection of some cancers to target and proliferate in the bone is also unclear.

Palliative embolization. Embolization is useful for the treatment of metastatic bone disease as an adjunctive procedure to devascularize the tumor, reduce the size of the metastases, cause calcification of the margins of the tumor, and relieve pain. It is typically performed at 4- to 6-week intervals until symptoms improve or until the tumor's vascularity disappears, as indicated by angiography, MRI, or CT scan.[59] Embolization therapy does not appear to improve survival, but it may provide palliation and improve QOL. Previous studies have associated embolization with reduced pain and tumor volume lasting from 1 to 9 months.[59]

Radiofrequency ablation (RFA). RFA is a form of electrosurgery in which an alternating current of high-frequency radio waves passes from an electrode tip into human tissues and dissipates its energy as heat.[65] RFA has emerged as a safe, easy, and predictable technique for thermal ablation in the liver, kidney, heart, prostate, breast, brain, lung, lymph nodes, thyroid and parathyroid glands, nerve ganglia, and bone.[65] In the past two decades, use of RFA for the treatment of primary or metastatic bone disease has increased.

HIFU. HIFU has been described as a safe, completely noninvasive, and extracorporeal method to treat primary solid tumors and metastatic bone disease.[66] The treatment rapidly delivers the energy required to raise tissue temperature to a cytotoxic level so the tissue vasculature does not significantly affect the extent of cell lysis.[59] Although in its infancy, HIFU appears to be a safe, noninvasive, promising treatment approach for cancer patients with bone metastases.

Pathological Fracture Treatments

Because of the high mortality related to pathological fractures, the risk factors associated with metastatic bone disease remain poorly understood. This knowledge is necessary for the prevention, detection, and treatment of pathological fractures. Risk factors for pathological fractures in patients with bone metastasis include increasing pain, radiographic osteolytic appearance, lesion size (>25 cm), axial cortical involvement (>30 mm), and circumferential cortical involvement (>50%).[67]

Surgical treatment is a good option for patients with metastatic or impending pathological fractures and solitary metastatic lesions. Treatment must be tailored individually, considering the estimated life expectancy and general condition of each patient. The treatment goals are to reduce pain and restore function for the duration of the expected life span. A population-based study of patients with femoral metastasis showed that patients who received prophylactic stabilization of metastatic bone disease had better survival outcomes than those who received surgical interventions post fracture.[68]

Conclusion

The urgent syndromes presented in this chapter are discussed to educate, empower, and equip current and future palliative care nurses. Because many of these topics are emergent in nature, the palliative care nurse must be prepared to provide optimal patient care specific to the disease and to educate patients and family members. EOL care is all about maintaining hope and dignity even when urgent syndromes affect the patient.

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CHAPTER 27

Sedation for Refractory Symptoms

Chandana Banerjee and Bonnie Freeman

Key Points

- Palliative sedation or continuous deep sedation is used during the final days to hours of life to control symptoms such as pain and restlessness, refractory to aggressive palliative treatment.
- Palliative sedation differs from euthanasia in that the medical provider's goal is to relieve refractory symptoms, not to end the patient's life.
- Palliative sedation requires expertise, collaborative decision-making and support, knowledge of ethical and legal issues, ability to understand the dynamics of suffering, informed consent, and a compassionate and therapeutic presence.
- Palliative sedation varies by provider and is an individualized end-of-life care option that focuses on the relief of a patient's unique refractory symptoms by dosing to effect. There is no maximum dose, and there is no one universal treatment plan.
- Palliative sedation effectively addresses the basic ethical principles of dignity, autonomy, fidelity, beneficence, and nonmaleficence.

Introduction

To fully understand the important role palliative sedation can play in the control of intractable pain and suffering for a dying patient, one must understand how the body shuts down during the dying process, the legal precedence for the use of palliative sedation, the specific goals of palliative sedation, and the patient's right to define what he or she perceives as suffering. It is also important for the healthcare professional to examine his or her own cultural, religious, and personal beliefs and how they may affect the ability to care for a patient undergoing palliative sedation.[1–9]

The Dying Process

During the dying process the body struggles to make the most effective use of available oxygen.[10] Its main focus becomes the preservation of cardiac, pulmonary, and cerebral function. All other systems experience a marked reduction in perfusion and function.[10,11]

- *The gastrointestinal system* undergoes a severe reduction in peristalsis, progressing to the loss of the ability to swallow. This contributes to a normal loss of appetite. Any food or fluid provided can result in vomiting, aspiration, abdominal distention, and pain. The loss of appetite and ability to eat may not be well accepted by a society that embraces food as a form of love and comfort. The fear of starving a loved one to death can result in the use of continuous tube feedings and forced feedings that can hasten death. The feedings may cause the patient to expend precious energy and create the likelihood of aspiration.[10,11]
- *The nervous system* is deeply affected by circulating toxins and waste products from progressively failing organs such as the kidney and liver. These toxins are particularly irritating to the cells of the brain and can result in confusion, agitation, and delirium. This is also heightened by the natural dehydration and hypoperfusion that occurs as part of the dying process. The dying will sleep more in an effort to conserve energy and will be less responsive as a result of reduced cerebral perfusion and cellular death. They will not be interactive with family and friends, and cognitive function will become progressively more impaired. Involuntary body functions such as breathing, will become more dependent upon the involuntary stimulus of the brainstem.[10,11]
- *The respiratory system* undergoes a dramatic change as the brainstem takes over involuntary function. Respirations become agonal and irregular, as the lungs continue to struggle to pull in oxygen. Blood pressure is insufficient to effectively maintain the required pressure gradient for oxygen transport, and fluid begins to accumulate in the lungs, causing the congestive "death rattle." Suctioning does not reduce these secretions; it only deprives the dying patient of more oxygen. High-dose supplemental oxygen will only prolong the dying process.[10,11]
- *The circulatory system* attempts to adjust to a continued drop in blood pressure, resultant loss of oxygen, and the loss of circulating protein. Colloidal osmotic pressure cannot be maintained, so fluids introduced into circulation have only a short time to influence blood pressure and cellular perfusion before they seep into surrounding tissues and ultimately accumulate in the lungs. Increasing intravenous fluids can result in massive pulmonary edema and cause a patient to die more quickly. The heart begins to fail as its energy needs cannot be met to continue to beat effectively. As cells die, there is an increased release of potassium and irregular heart rhythms worsen until finally the heart can only quiver, no blood can circulate, respirations cease, and brain cells continue to die.[10,11]

Legal Precedence for the Use of Palliative Sedation

The concept and use of palliative sedation or continuous deep sedation has evolved over the past 25 years and is no longer called terminal sedation, a term first coined by Enck in 1991. By 2010, the term "palliative sedation" was used consistently when describing the monitored administration of medications to induce sedation in an effort to control refractory and unendurable symptoms near the end of life.[2]

"Palliative sedation is not only a legal act; it is grounded in basic ethical precepts including dignity, autonomy, fidelity, beneficence, nonmaleficence, and the principal of double effect."[2 (p. 397)]

- *Dignity* involves an individual's right to be perceived as worthy of honor and respect. This personal desire involves the ethical concept of autonomy; individuals fear the loss of control over their bodies in the dying process, and this loss of control equates to the loss of dignity.
- *Autonomy*, also referred to as self-determination, is a core belief in the United States and is based on the principle of respect. It addresses the right of an individual to decide a course of action based on his or her personal goals and values.
- *Fidelity* is the commitment of healthcare professionals to keep our promises to patients and family members and not to abandon them and their needs, especially during the dying process.
- *Beneficence* involves doing good and caring for patients in a way that they would want. This typically is reflected in the management of their refractory symptoms.
- *Nonmaleficence* is the standard of not causing harm through omission of care or not following a patient's request that could result in a loss of their dignity, diminish their autonomy, result in abandonment, or ignore their care wishes.
- *Principle of double effect* acknowledges that there can be both good and bad consequences to an action, but the action is undertaken with the hope (ethical/moral) or intent that the good consequence will occur.[2] "Potentially causing complication or hastening death is not the means or the intent of the action so the use of palliative sedation is morally permissible."[2 (p. 397)]

The intent of palliative sedation is to control symptoms, not hasten death.[2,3] "Intent," was identified by the US Supreme Court as one of the dominant factors required to be proved when trying to establish a standard for euthanasia.[12,13]

In 1997, the US Supreme Court ruled unanimously that "there is no constitutional right to physician-assisted suicide" but, palliative sedation is "intended for symptom relief and not assisted suicide, and is appropriate in the aggressive practice of palliative care."[12,14,15] The American Nurses Association and the Oncology Nursing Society have position papers opposed to physician-assisted suicide.[16,17] Although neither of the position papers addresses the exact issue of palliative sedation, both support the risk of hastening death through treatments aimed at alleviating suffering or controlling symptoms as ethically and legally acceptable. The Hospice and Palliative Nurses Association has also issued a position paper in support of palliative sedation.[18] The use of palliative sedation to address existential suffering remains controversial.[19]

The use of palliative sedation requires three basic elements: (1) a need for relief of intractable symptoms, (2) death is estimated within days to hours, and (3) there is a need to involve medications to reduce awareness.[4] The concept of *proportionality* is another legal precedent used to justify the amount of medication required to reduce awareness. The patient's consciousness is lowered just enough to relieve refractory suffering.[9,20] Proportionality is also a factor referenced when attempting to clearly separate palliative sedation from euthanasia. The intent of palliative sedation is to allow the patient to die comfortably and peacefully at a pace set by their body.[8]

The benefits of palliative sedation should be stressed over the concerns of accelerating the dying process.[9] Refractory symptoms such as pain, delirium, and existential suffering can be controlled, and concerns over the loss of communication, starvation, dehydration, and fears of euthanasia must be weighed against the comfort benefits obtained from deep sedation and the fact that many of the disadvantages identified with the use of palliative sedation occur naturally during the dying process.[8,9]

An informed consent should be obtained prior to the use of palliative sedation. Ideally, informed consent should be obtained from the terminally ill patient.[2,3,8,9] Often, informed consent is obtained from the family, next of kin, or someone with a durable power of attorney who is designated as able to make decisions for the patient. Advance directives, extensive education, and planning are helpful strategies to prepare patients and their families for end of life, and these can greatly assist with the promotion of a peaceful death.[9]

The Goal of Palliative Sedation

The goal of palliative sedation is to provide a medically induced level of unresponsiveness for relief of refractory suffering during the actively dying process.[21,22] Palliative sedation is not intended to accelerate the dying process. Patients and their families should discuss its use as refractory symptoms are identified.[23,24] A plan to use palliative sedation should be instituted as part of a natural dying process to assist in the promotion of a comfortable, compassionate, and peaceful death.[2]

Impact of a Care Provider's Personal, Cultural, and Religious Beliefs

It is essential that the healthcare provider is aware of his or her personal views and biases regarding palliative sedation.[21,26] If the provider has a spiritual or personal objection, removal from direct patient care should be accommodated. Often the healthcare provider can become more comfortable if the purpose and implementation of palliative sedation is explained. There will continue to be objections for its use, but the requests of the dying patient and their family must take precedence. A semi-structured interview-based qualitative research study conducted by DeVries and Plaskota[25] exploring the ethical dilemmas faced by seven hospice nurses when administering palliative sedation to patients with terminal cancer concluded: "Hospice nurses need to be confident, competent, and well supported within the expert palliative care team when faced with making decisions about the use of palliative sedation."[(p. 155)]

The Patient's Right to Define Suffering

Suffering at the end of life may involve physical, psychological, social, or spiritual distress. In most situations, multidisciplinary palliative interventions can effectively comfort, but in some instances, suffering becomes refractory and intolerable.[2,3] Existential suffering (sometimes referred to as *terminal anguish*) is a more ethically challenging reason for the use of palliative sedation, but it has an important impact on quality end-of-life care.[19] The ability to empathize, to understand the need for hope and optimism and the desire of an individual to have meaning for his or her suffering are often poorly understood concepts by the healthcare professional and can cloud the importance of relieving personal and spiritual suffering.

Case Study: Existential Suffering

Edward was an example of a patient experiencing existential suffering. He was a 38-year-old man who had been fiercely independent all his life. He developed metastatic rectal cancer and now required help with all of his ADLs. This was intolerable to him, especially when he required help after his frequent episodes of incontinence. His pain was controlled with opioids, but he began to have terror attacks when he required any assistance. He begged his primary team to sedate him as his strength further declined, and he was finally placed on a continuous midazolam infusion. He died peacefully 3 days later. Was palliative sedation necessary for this man? By his standards, and the emotional suffering he was enduring, it was. The healthcare staff had difficulty sedating him even though his condition met the three basic elements for palliative sedation: (1) a need for relief of intractable symptoms, (2) death was estimated within days to hours, and (3) there was a need to involve medications to reduce awareness.[4] Several nurses declined to care for him after palliative sedation was initiated.

The use of palliative sedation for existential suffering remains challenging from ethical, personal, and professional standpoints. There should always be the option for healthcare staff to request that they not be involved if they hold strong beliefs against the providing of palliative sedation. An important concept to consider is that the goal should always be to provide quality end-of-life care as the patient defines it. For Edward, palliative sedation was the right choice for him.[12,19,20]

Medications Routinely Used for Palliative Sedation

Bodnar[7] surveyed 381 physicians regularly caring for hospice/palliative care patients and noted that 84% had moderate to no experience with palliative sedation, and only 88% had participated in palliative sedation in the past 5 years. The option to provide palliative sedation does not occur often, and its implementation can vary greatly by provider. There are varying definitions of the process, and no one standardized procedure exists.[7] Drugs most commonly used for palliative sedation include benzodiazepines, barbiturates, and propofol.[7] Additional agents such as opioids and psychotropic drugs like haloperidol and opioids are incorrectly given for their secondary sedating effects. "In end-of-life-care, medications indicated and used to address specific symptoms with a subsequent reduction in the level of consciousness to a varying degree as a side effect should not be used for sedation."[7(p. 17)] Haloperidol is the gold standard for delirium therapy and agitation. Opioids are designed to address pain and respiratory distress. Haloperidol is unreliable for complete sedation, and it is possible for some patients to have no response to it at all for delirium.

In addition to the use of medications not specific to providing sedation, actual levels of sedation can vary. Proportional sedation is recommended as a guideline. It requires that sedation be provided only to the point of symptom relief. In most areas of the United States, palliative sedation is considered deep continuous sedation as the patient is rendered unresponsive.[7,26,28] In other areas of the world, palliative sedation can take two distinct forms: one where the goal is to preserve alertness as much as possible, and the other is to sedate to unconsciousness because the patient's intractable symptoms are so profound.[7] In-depth discussions should be held with the patient and family to confirm their wishes for the level of sedation. In most instances, palliative sedation is not discussed until symptoms are too severe and intractable, so deep sedation is typically the standard of practice.

Bodnar noted that the most recommended agents used for palliative sedation are midazolam, lorazepam, diazepam, phenobarbital, and propofol (see Table 27.1).[7]

Midazolam is the most commonly used of the recommended palliative sedation-producing drugs.[7,28] It has a rapid onset of 60 seconds, a peak effect in 2–5 minutes, a half-life of 1–3 hours, and a duration of action of slightly less than 2 hours. There is a ceiling effect for central nervous depression found with all benzodiazepines. This can result in midazolam being ineffective over time. In cases where rapid sedation is required, midazolam can be given in 5–10 mg intravenous doses every 5 minutes to a maximum of 20 mg. Dosing beyond 20 mg has little to no efficacy, and another agent will be needed.

Since duration of effect is an important consideration for effective midazolam use, continuous infusions should always start with a bolus, and rates can be adjusted every 1–2 hours with additional boluses.[7]

Lorazepam is a favored benzodiazepine for prolonged palliative sedation cases anticipated to extend for greater than 24–48 hours because it begins to retain more than half of its effect after 4 hours of sustained sedation. It is a commonly administered drug, so nurses are more comfortable with its use. Lorazepam requires 20–30 minutes to reach full effect, and initially, all effects will wear off in 1–2 hours unless prolonged sedation is delivered.[7,21,29]

Diazepam, is a much older and fast-acting benzodiazepine. Its rapid peak onset of 2–5 minutes makes it a valuable resource when rapid sedation is required. Its duration of effect is half that of midazolam, but the need for large volumes of fluid to dilute, its tendency to precipitate out of solution, and its cumulative effect resulting in a long half-life has caused diazepam to become unsuitable for long-term and continuous sedation. Its use in palliative sedation is primarily as a supplemental agent.[7]

Phenobarbital can be given subcutaneously, like midazolam, although this is not an approved route by the manufacturer. The ability to give this drug subcutaneously makes it a valuable resource for sedation in both the hospital and hospice settings. Phenobarbital is stronger than midazolam and is often used when midazolam has proved ineffective, yet it is not a first-line agent used for palliative sedation because it was originally designed to treat intracranial hypertension and status epilepticus. It has a more extensive accumulation effect with repeated administration and with the use of a continuous infusion that can result in a half-life of 53–120 hours. Dosing in a hospice setting is 200 mg every 30 minutes, followed by intravenous boluses of 260–1250 mg every 8 hours or a continuous infusion of 30–160 mg/hr.[7]

Propofol is slowly gaining popularity as an option for use in palliative sedation. It was specifically designed for sedation and anesthesia. It has no central nervous system depression ceiling effect, a rapid onset and peak effect, a short half-life, and a duration of

Table 27.1 Medications used for palliative/continuous deep sedation

Medication	Effect	Peak effect	Bolus	Infusion	Considerations
Midazolam	1 min	2–5 min bolus 50–60 min infusion	2–5 mg q5min max of 20 mg	1–20 mg/hr titrate q1hr + bolus dose 0.7–10 mg/hr	Short half-life, give IV or SQ, central nervous system ceiling, variable effect
Lorazepam	5 min	30 min	4 mg q4h repeat q30min if no other agents available	20–40 mg 250 mL 1 mg/hr after 4 mg bolus, max 7–10 mg/hr	Prolonged time to peak effect, best for prolonged sedation. Peak effect lasts 4 hours
Diazepam	1 min	2–5 min	5–10 mg q5min max of 30 mg	5 mg in 100 mL will be stable for 24 hours	Very rapid onset to peak effect, best for deep sedation. Need large dilution for IV precipitates
Phenobarbital	5 min	30 min	200 mg q30min min effective dose ~100 mg	None Give 10% of loading dose q12h	Often effective with midazolam failure. Long half-life, accumulation. Difficult to titrate
Propofol	30 sec	90 sec	0.5–1 mg/kg, may repeat ½ of loading dose	1 mg/kg/hr or 15 mcg/kg/min titrate 5–10 mcg/kg/min q20min	High risk of side effect with large loading dose given rapidly CNS depression ceiling Always effective in sufficient doses

Source: From Bodnar J. Review of agents for palliative sedation/continuous deep sedation: pharmacology and applications. *J Pain Palliat Care Pharmacother* 2017;31(1):16–37.

effectiveness of 2–6 minutes. There are only a few published studies on its use for an estimated 4% of all palliative sedations provided in the United States. Dosages for propofol are significantly smaller for palliative sedation than those required for anesthesia. Yet propofol is not a first choice for many healthcare providers due to policies that prevent its administration in unmonitored areas, requirement for its use to occur only with the failure of other sedating agents, and the lack of experience with the drug.

Palliative Sedation Nursing Care

The bedside nurse is an essential part of the palliative sedation team. Each physician will differ with his or her titrating criteria, but the goal for the provider is to keep the dying patient as comfortable as possible and allow the patient's body to shut down naturally without suffering. Sedation usually includes a continuous opioid infusion and the use of a benzodiazepine. Sedation is proportional in that the amount of sedation is in proportion to the patient's body requirements to be kept deeply and continuously sedated. The bedside nurse may need to stay in close communication with the prescribing physician, nurse practitioner, or physician's assistant for more specific directions or concerns.[30]

Family members become distressed if they feel their loved one is suffering, so the nurse should have orders available to him or her to address these concerns. Education and a continued presence are often required. Grieving friends and families of loved ones may not absorb information provided only once, so the bedside nurse should be prepared to re-explain all teaching as necessary. There will be a need to reinforce to friends and family members that palliative sedation is not intended to speed up the dying process, nor is it causing additional suffering because their loved one can no longer eat or drink. The normal course the body takes in shutting down during the dying process should be emphasized, as discussed in an earlier section of this chapter. The dying have a natural loss of appetite, thirst, and desire to communicate. Often the loss of these associated interactions is difficult for grieving families, and they will require frequent reassurance.[31,32]

General care for a patient undergoing palliative sedation becomes much like any other dying patient's care. The sedation has simply allowed them to be less restless and have their intractable symptoms controlled.[30]

> One family member stated that once he was sedated, they were actually able to spend a lot of quality time together. They played music that they played at their wedding, and he was so much more peaceful. She laid on the bed with him, and she slept in the room. And because he was in this state rather than the aggressive one, they were able to spend a few days of some quality time together without his last day of his life being agitated and aggressive. . . . He was settled and peaceful.[9(p. 153)]

Conclusion

Many nurses and healthcare professionals remain uncomfortable with palliative sedation. Often, this discomfort can be attributed to a lack of understanding of the ethics that guide the providing of palliative sedation and what transpires in the normal dying process. Patients with intractable symptoms that cause them to suffer on any level as they die need their symptoms to be addressed. Palliative sedation does not speed up the dying process, and it is not a form of slow euthanasia. Healthcare providers may not all agree about how to define a "good death," but there is a general understanding about what constitutes a "bad death." Palliative sedation is a reasonable and ethical option for patients with refractory and intolerable symptoms and suffering at end of life, and for many it is essential for a compassionate and peaceful death.

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CHAPTER 28

Complementary and Integrative Therapies in Palliative Care

Mary-Anne Meyer and Melinda Ring

Key Points

- Patients with chronic illness frequently use integrative medicine to help address symptoms and improve quality of life.
- Evidence of efficacy of specific therapies for common concerns such chronic pain, mood issues, and gastrointestinal symptoms is growing.
- The nursing profession plays a critical role in guiding patients and families in the safe and appropriate use of integrative medicine for palliative care.

Integrative Medicine and Palliative Care: The Critical Role of Nurses

Integrative medicine aims to provide whole-person care with a focus on healing and health rather than curing and disease, and thus it is inherently aligned with palliative care. Incorporating the broader toolbox of therapeutic practices, a social-spiritual emphasis, and a compassionate partnership between provider and patient (and family/support persons) can be of benefit at any time from diagnosis to end-of-life care. Earlier adoption is encouraged to allow for greater potential benefits. For many patients and families, beyond the actual relief of symptoms and management or reversal of disease processes, active engagement in an integrative approach provides a sense of empowerment over their disease; this paradigm shift can be healing in and of itself. Nurses on the front-line of caring for patients with chronic debilitating symptoms and end-of life care are ideally positioned to help patients understand their options and facilitate access to safe and appropriate resources. The nursing profession additionally has deep roots in the philosophical approach to holistic, relationship-centered healing. This chapter serves as an introduction to frequently encountered terminology, complementary and integrative medicine (CIM) practices, and current evidence for common concerns addressed via an integrative palliative care approach.

Current Prevalence of Complementary and Integrative Therapies in Palliative Care

In the United States, approximately 38% of adults (about 4 in 10) and approximately 12% of children (about 1 in 9) are using some form of CIM.[1] Previous studies have shown that individuals opt to use CIM to improve health and well-being, to relieve symptoms associated with chronic diseases, or to manage side effects of conventional medicine.[2] Palliation of chronic pain and management of symptoms and side effects related to oncology care are among the top conditions for which patients report using CIM.[3,4]

In response to growing awareness in the medical community, integrative medicine services are increasingly available in academic and community health centers. The Academic Consortium for Integrative Medicine and Health membership increased from 9 North American academic institutions in 1999 to 69 in 2017.[5] The US military health system has been an early adopter of the use of integrative strategies for their stakeholders, especially in relation to its benefits for managing pain. In 2010, the Department of the Army Pain Management Task Force published its report with the recommendation for a comprehensive pain management strategy focused on an interdisciplinary, holistic, multimodal, patient-centered approach.[6] A survey of 14 Department of Defense medical treatment facilities found that 100% of the 14 facilities offered IM services, with 92% offering six or more modalities.[7] The research literature also documents a growing number of integrative oncology programs; at least 29 dedicated CIM oncology programs were noted, with many more integrative centers offering care to cancer populations.[8]

Hospice programs have also incorporated CIM options, with prevalence increasing over recent decades. In surveys from the early 2000s, 60–70% of responding hospice organizations offered CIM therapies.[9,10] The most common services were massage therapy (83%), music therapy (50%), therapeutic touch (49%), pet therapy (48%), guided imagery (45%), Reiki (36%), aromatherapy (30%), harp music (23%), reflexology (20%), art therapy (20%), hypnotherapy (4%), yoga (3%), acupuncture (1%), and humor therapy (1%).[9] A recent survey of 108 Illinois-based organizations listed on the National Hospice and Palliative Care Organization website found that 90.3% of the responding organizations offered some type of CIM.[11] The top five most frequently offered options in this report were pet therapy (64.5%), music therapy (61.3%), massage therapy (54.8%), art therapy (29.0%), and energy therapies (25.8%). However, even in hospices and palliative care programs that offer these services, they are accessed by less than 25% of eligible patients.[10] Profit orientation and the number of patients served by hospices have been identified as significantly related to the probability that hospices will offer CIM.[12] Not-for-profit hospices were approximately four times more likely to offer CIM than for-profit hospices, and for every 100 patients served by the hospices, the odds of offering CIM increased by 13%. Constraints to providing and use of these services include lack of funding, lack of staff time, lack of qualified therapists, inadequate knowledge about these services, and patient and staff resistance to the services.[9] Preliminary research outcome data on CIM programs have been favorable, and Demmer and Sauer found that patients who received complementary therapies were more satisfied with their hospice services.[13,14]

Patients may seek integrative medicine on their own or be referred by members of their healthcare team. A National Institute of Health (NIH)-funded study found that referrals to integrative medicine inpatient services at a tertiary hospital were often driven by nurses and mid-level providers.[15] In this survey, physicians and administrators indicated that nurses were better able to assess a need for CIM services, initiate discussions about them, and consequently recommend them to patients. In contrast, a survey about physician attitudes toward and knowledge about CIM reported that 76% had never referred a patient to a CIM practitioner, although 44% stated that they would refer a patient if a practitioner were available at their institution.[16] An online survey of professional members of the German Society for Palliative Care confirmed the stronger interest among nurses: among the 365 respondents (9.8% of all members), 85% of the physicians and 99% of the nurses claimed to be interested in CIM.[17] Combined, these findings highlight the important role of nurses in guiding patients to ensure safe and appropriate utilization of CIM services and therefore educating themselves on potential benefits versus risks for commonly seen conditions. The remainder of this article aims to provide an introduction for nurses to integrative health, with resources for additional learning and reference.

Terminology

It is helpful to have shared definitions when describing holistic system approaches to healthcare and the individual healing traditions and practices. The following basic terms are recommended by the National Institute for Health's National Center for Complementary and Integrative Health (NCCIH)[18]:

- *Complementary health approaches*: Practices and products of non-mainstream origin
- *Integrative health*: Incorporating complementary approaches into mainstream health care

A broader definition of integrative medicine as promoted by the Osher Collaborative, an international group of six academic centers funded by the Bernard Osher Foundation to study, teach, and practice integrative medicine follows.[19]

Integrative medicine:

- Reaffirms the importance of the relationship between practitioner and patient, focuses on the whole person, is informed by evidence, and makes use of appropriate therapeutic approaches, healthcare professionals, and professions to achieve optimal health and healing.
- Applies rigorous scientific research methods to evaluate physiological and therapeutic mechanisms, efficacy, and use of approaches in society as they affect health, resiliency, and well-being.
- Educates practitioners, public, and policy to appreciate and address the full range of physical, emotional, mental, social, spiritual, and environmental influences that affect health.

Other descriptors of approaches to patient care that overlap with integrative medicine:

- *Alternative medicine* refers to the much less common occurrence of a non-mainstream practice being used in place of conventional medicine.
- *Functional medicine*, according to the Institute for Functional Medicine, determines how and why illness occurs and restores health by addressing the root causes of disease for each individual. It requires a "detailed understanding of each patient's genetic, biochemical, and lifestyle factors and leverages that data to direct personalized treatment plans that lead to improved patient outcomes."[20]
- *Holistic medicine*, according to the American Holistic Health Association "is the art and science of healing that addresses the whole person—body, mind, and spirit. The practice of holistic medicine integrates conventional and alternative therapies to prevent and treat disease, and most importantly, to promote optimal health."[21]
- *Lifestyle medicine*, per the American College of Lifestyle Medicine, "involves the use of evidence-based lifestyle therapeutic approaches, such as a predominantly whole food, plant-based diet, exercise, sleep, stress management, alcohol moderation and tobacco cessation, and other non-drug modalities, to prevent, treat, and, oftentimes, reverse the lifestyle-related, chronic disease that's all too prevalent."[22]

Complementary Health Approaches

There is overlap in the practice and proposed mechanism of different complementary health approaches; therefore, the NCCIH currently suggests considering them within two major subgroups: natural products or mind-body practices.[18]

Natural products include a diverse group of substances that includes vitamins, minerals, and probiotics, as well as compounds from diverse sources. Many natural products are produced from marine organisms, bacteria, fungi, and plants, herbs and botanicals.[23] Natural products can include complex extracts from whole plants or isolated compounds. In traditional herbalism, whole-plant extracts are often used due to purported positive synergistic interactions, while a more Westernized approach seeks to isolate the active compound.[24,25] According to the 2012 National Health Interview Survey (NHIS), 17.7% of American adults had used a dietary supplement (not including vitamins and minerals) in the past year, making them the most popular form of complementary approaches in the survey.[2]

Mind-body practices include a large set of techniques ranging from meditation, yoga, and tai chi to acupuncture, massage, and chiropractic manipulation. These practices are often taught or provided by a trained teacher or practitioner, though self-use is also common.

A third category of *whole healing traditions* incorporates many aspects of both natural products and mind-body approaches. Examples of these include Ayurvedic medicine (the traditional medicine of India), traditional Chinese medicine, naturopathy, and traditional healers.

Applications in Palliative Care

Conventional medicine excels at treating emergency situations, acute conditions such as infection, and problems requiring a surgical intervention. However, many chronic conditions are not fully amenable to treatment with conventional medicine approaches, or the side effects and risks significantly impair a patient's quality of life (QOL). In these cases, an integrative strategy can often provide important relief. Here, we focus on three categories of frequently encountered issues with examples of current research behind potential therapeutic options: (1) chronic pain, (2) fatigue and mood disorders, and (3) gastrointestinal conditions.

Case Study: Integrative Medicine

Aurelia was a 55-year-old woman with a recent diagnosis of Stage 1B hormone-receptor-positive breast cancer who presented with insomnia, fatigue, and joint stiffness. She was diagnosed after an abnormal finding on her routine mammogram and subsequently underwent a lumpectomy with axillary node dissection, chemotherapy, and radiation therapy. She was started on the aromatase inhibitor letrozole 1 month ago. Prior to being diagnosed, her health history was unremarkable other than being overweight (body mass index 29). She had significant personal stressors in her life including the death of her father during cancer treatment and the end of her marriage of 20 years last year. She reported trouble both falling asleep and staying asleep. She was prescribed many medications but preferred to take nonpharmaceuticals. She presented to the integrative medicine team for "holistic treatment."

Integrative Medicine Plan and Response

The initial integrative medicine consult consisted of an in-depth discussion of Aurelia's view of her illness, goals for her health, and understanding of her current social, spiritual, emotional, and environmental aspects of well-being.

Psycho-social-spiritual: In discussion, it became clear that, in many ways, Aurelia had been compartmentalizing her feelings in order to focus on the demands of her healthcare during treatment. She noted a feeling of tightness or heaviness in her chest that she associates with her emotional and physical fatigue. She noted never having time to grieve the loss of her father due to her own illness, and additionally didn't fully process the grief of the loss of her marriage, and now the loss of her health as the one thing she saw as intact in her life. Her cardiac evaluation was normal, and she did work with a therapist in cognitive behavioral therapy (CBT) weekly for the past year.

Recommendation: The grief and emotional stressors were not the sole cause of fatigue, but could be significant contributors. Aurelia found CBT helpful as a support but didn't feel like it helped her fully process her emotions. Energy therapy with Reiki was suggested, with a discussion about how traumas sometimes benefit from a therapy that works at a different level and can help move "stuck" emotions and support healing. She was additionally taught a brief Loving Kindness Meditation (LKM), to send loving emotions to herself and to troubling situations. Aurelia had been exploring essential oils and chakra/energy readings, so this approach was very appealing to her. She saw an experienced Reiki practitioner at the Osher Center weekly for 8 weeks and did the LKM meditation twice daily. At her follow-up visit she noted that, in her first few treatments, she had deep releases where she was sobbing on the massage table. She said after this early session that she felt a bit drained, but also cleansed. At the end of 2 months, she noted no longer feeling any chest tightness; she felt lighter, and while she still struggled with feelings of loss they were more manageable. Her sleep was improved and more restorative. She planned to continue Reiki sessions monthly, continue the meditation practice, and still see her therapist twice monthly as she created her vision for what came next.

Musculoskeletal: The joint aching was clearly associated temporally with starting the aromatase inhibitor. She noted this was a barrier to her being physically active, as she knew the importance of both physical activity and weight management for reducing the risk of breast cancer recurrence. She was considering stopping the medication unless the symptoms could be controlled.

Recommendation: The data on acupuncture for her situation were reviewed with Aurelia. She had received acupuncture during her chemotherapy sessions in the infusion suites by Osher center acupuncturists, and she felt they helped minimize her symptoms. Given her positive experience, she was interested in exploring this option. She began acupuncture sessions in the Osher Center, and was also given Traditional Chinese Medicine (TCM) herbs based on her TCM diagnosis. At the 2-month follow-up she noted some improvement in the symptoms starting at the fourth session. Given the positive trend, she planned to continue to see if she could have complete resolution.

Prevention: Aurelia had already received basic nutrition and physical activity counseling through the Cancer Survivorship program. She was making positive changes but sought additional counseling and wondered if she should be taking any dietary supplements. A full dietary and physical activity history was taken, and while she had been making some positive changes, her prior diet was low in vegetables, fruits, and fibers and had daily added sugars and refined carbohydrates. Lab tests revealed vitamin D deficiency and low essential fatty acids. Vitamin D supplements and fish oil were recommended, along with a shift toward a whole-food plant-based diet. Given her prior sedentary lifestyle and joint discomfort, she started an exercise regimen that included longer daily walks at a higher intensity and twice-weekly restorative yoga classes. At 2-month follow-up she had lost 5 pounds and was ready to increase her program, so 30 minutes of high-intensity interval training was added twice a week.

Chronic Pain

Pain is a complex phenomenon involving physical, emotional, social, and spiritual aspects that all must be addressed. Depression, anxiety, and spiritual distress can all increase the perception of pain intensity, and addressing these components can reduce the need for pain medication.[26] A comprehensive review of all effective integrative and complementary therapies for these concerns is impossible given the enormous diversity in this area. This chapter will share some of the most current data on mind-body approaches (e.g., movement, relaxation therapies, music, aromatherapy, massage, and acupuncture), and then review common dietary supplements for symptom management in serious illness or at end of life. Many modalities are quite effective for a number of symptoms in palliative care and have been studied in different populations.

Mind-Body Approaches for Pain

Physical Activity

Patients with cancer are often discouraged from engaging in exercise during cancer treatment, but the positive effects of continuing exercise on QOL, weakness, fatigue, and mood are documented in a number of studies.[27] A 10-year longitudinal study of post-treatment breast cancer patients showed that pain was significantly reduced in patients who maintained regular physical activity and an ideal body weight, as opposed to those women who had a weight gain of more than 5%, who were obese or overweight, and had a sedentary lifestyle.[26]

Massage Therapy

Massage therapy encompasses many different styles, but in patients with advanced chronic illness, gentler forms such as Swedish massage may be better tolerated. In a meta-analysis of studies involving massage for adult oncological patients receiving palliative care, 4 of 6 studies showed a statistically significant reduction in pain.[28] Other studies looking at the lasting benefits of massage on pain were less favorable, showing that the immediate benefits of massage seem to be higher than the longer term effects. Qualitative data from studies have also shown that interventions such as massage therapy seem to be effective if the patient is treated with empathy and if a relationship between the massage therapist and the patient had been formed beforehand.[29]

Aromatherapy

Aromatherapy—the therapeutic use of essential oils—is an increasingly popular option for use by nurses in inpatient and palliative care settings. The aromatic organic compounds are typically applied in one of three ways: (1) inhalation; (2) topically during baths, massage, or on a compress; or (3) through oral ingestion. A 2016 meta-analysis of 12 studies examined the use of aromatherapy for pain management.[30] It concluded that there was a significant positive effect of aromatherapy compared to controls (placebo or treatments as usual) in reducing pain reported on a visual analog scale, with stronger correlations found in nociceptive and acute pain versus inflammatory and chronic pain. Lavender was the most commonly studied essential oil, with others being orange, eucalyptus, clary sage, chamomile, rose, ginger, rosemary, peppermint, and lemongrass. Applications included hand massage, localized massage, acupressure, sitz baths, and vaporized, and the populations included children, pregnant women, and patients with chronic pain or in hospice. Many patients and healthcare providers are attracted to aromatherapy because of its low cost and minimal side effects.[31]

Acupuncture

Acupuncture involves the insertion of fine sterile disposable needles into specific body points along energy pathways known as *meridians* to address imbalances and thereby alleviate symptoms and prevent or treat disease. Traditional Chinese acupuncture is based on the health concept of Qi ("chee") or vital life force energy. Many studies and systematic reviews have been done but are generally not considered to be of sufficient quality to reach conclusions. However, a 2012 analysis of acupuncture for pain showed improved pain relief in patients who received acupuncture for back or neck pain, osteoarthritis, or chronic headache.[32] A 2016 meta-analysis of 20 randomized clinical trials (n = 892) reported that acupuncture alone was not superior to pharmacotherapy for cancer-related pain; but, of significance is that combination therapy may be more effective, resulting in quicker pain relief, longer pain remission, and improved QOL.[33] At the Sao Paulo Cancer Institute, 183 patients were enrolled in an acupuncture study that showed significant reductions in cancer pain, chemotoxicity, lumbar pain, and chronic postoperative pain.[34] Individual studies on acupuncture or electroacupuncture for aromatase inhibitor-related arthralgias suggest reduced pain and stiffness in treatment groups versus placebo or sham acupuncture, though these results did not achieve significance in a meta-analysis.[35] In 2016, the National Cancer Institute held a symposium on Acupuncture for Symptom Management in Oncology with a call to action for additional research.[36]

Music/Music Therapy

Simple music that is relaxing can be provided by anyone—typically healthcare staff—in what has been termed "music medicine." In contrast, in "music therapy" patients work with a trained music therapist in a therapeutic relationship where music (prerecorded, live, and/or interactive) is individualized based on a professional assessment.[37] The interventions in this review are generally classified as either *music medicine* or *music therapy*. In music medicine interventions, patients listen to prerecorded music that is administered by healthcare staff and preselected by study investigators, who may or may not have any formal training in music therapy.[7,8] Because there are a wide variety of modalities of music therapy, it has been difficult to perform reviews that give strong recommendations. Music can raise endorphin levels in the brain and lower adrenaline levels.[38] Music therapy has been studied in intensive care unit settings: Zimbardo and Gerrig found that 30 minutes of classical music therapy equaled the relaxation effects of 10 mg of diazepam.[39] Two recent studies in inpatient palliative care units suggest music therapy in this setting is feasible, well-received, and associated with promotion of relaxation and well-being.[40,41]

Mindfulness

Mindfulness-based stress reduction (MBSR) is an 8-week program of teaching moment-to-moment awareness of mind-body interactions through practices such as meditation, Hatha yoga, breath awareness, and body scan meditation. A meta-analysis review of studies using MBSR was significantly correlated with reductions in the anxiety, chronic pain, stress, and depression often found in patients at the end of life.[42]

Guided Imagery

Guided imagery has been shown to reduce anxiety, pain, and stress and to promote relaxation in some small trials.[43] Through guided imagery techniques, patients can learn to control functions normally controlled by the autonomic nervous system such as heart rate, blood pressure, respiratory rate, and body temperature. Through guided imagery, the patient can create an image of pain and then transform it into something less powerful and frightening.

Natural Products for Pain

Polypharmacy with nutritional supplements is to be avoided, similar to polypharmacy with medications, as these can increase the burden on the patient and caregiver without significant benefit as well as increase risk of interactions. In most cases of patients imminently dying, almost all nutritional supplements can be discontinued except for those giving specific symptom relief.[44] Supplements and herbs often utilized in pain management include turmeric, capsaicin, arnica, polyunsaturated fatty acids, vitamin D, and medical cannabis.

Curcuma longa (turmeric) has a growing body of evidence for the treatment of pain associated with osteoarthritis. This is likely related to the laboratory evidence showing that curcumin functions as a selective cyclooxygenase-2 (COX-2) inhibitor. A head-to-head clinical trial of curcumin supplementation in comparison with ibuprofen in the treatment of knee osteoarthritis demonstrated a similar treatment effect of each medication, with less gastrointestinal adverse events associated with curcumin.[45]

Capsaicin has been used topically for pain. Numerous studies have shown safety and modest efficacy of low-concentration formulations. A single 60-minute application in patients with neuropathic pain produced effective pain relief for up to 12 weeks. Topical capsaicin acts in the skin to attenuate cutaneous hypersensitivity and reduce pain by a process best described as "defunctionalization" of nociceptor fibers.[46] Over-the-counter (OTC) strength capsaicin (.025% to .075%) has been available for a long time, and studies did not show benefit beyond placebo.[47] More recently an 8% capsaicin patch has been used with more positive results.[48] A single patch applied for 30–90 minutes showed significant relief in the treatment of postherpetic neuralgia. The patch is difficult to tolerate as it causes a severe burning sensation and must be premedicated with topical lidocaine and even oxycodone. Capsaicin has also been studied in other conditions. Although enrolling only small numbers, the work done by Bhaskar and colleagues in cancer-associated neuropathic pain showed that almost 71% of patients in this subgroup had 90% pain relief.[49]

Arnica gel is an OTC product that has promising benefit. In 2013, a Cochrane Database Systematic Review concluded that "arnica gel probably improves symptoms as effectively as a gel containing nonsteroidal anti-inflammatory drug. . . . Comfrey extract gel probably improves pain, and Capsicum extract gel probably will not improve pain or function at the doses examined in this review. Further high quality, fully powered studies are required to confirm the trends of effectiveness identified in studies so far."[50]

It is thought that *omega-3 fatty acid* supplementation may have an anti-inflammatory effect.[51] Ramsden and colleagues performed a randomized controlled trial (RCT) examining the impact of omega-3 fatty acid supplementation for the treatment of chronic headaches. There was a significant reduction in the measures of headache intensity pain, in addition to increased markers of antinociceptive lipid mediators.[52]

There have been significant efforts examining the role of *vitamin D* in pain processing that involve complex pathophysiologic pathways. Earlier studies have demonstrated that high rates of hypovitaminosis D are prevalent in subjects with fibromyalgia and chronic pain. Several review studies have concluded that, although there seems to be a trend toward vitamin D supplementation and decreased pain, there is a need for further RCTs.[53] Considering that much time in hospice and palliative care is spent indoors and away from the best source of vitamin D, the sun, this is a worthy consideration.

Cannabis can potentially help alleviate neuropathic pain. Cannabinoid receptors are located in the central and peripheral nervous system (CB1) and the immune system (CB2). Numerous studies have shown safety and efficacy for central and peripheral neuropathic pain, rheumatoid arthritis, and cancer pain.[54] Studies in chemotherapy-induced peripheral neuropathy have shown that the activation of CB1 and CB2 receptors suppresses the development of vincristine-induced peripheral neuropathy in rats.[55] Nabiximols is an oromucosal spray of a formulated extract of the *Cannabis sativa* plant that contains the principal cannabinoids delta-9-tetrahydrocannabinol (THC) and cannabidiol (CBD) in a 1:1 ratio. It is available in Canada and Europe for treatment of peripheral neuropathy. Studies in the United States were not found to be clinically significant but showed promise, and further study is warranted.[56]

THC has been shown to enhance the analgesic effect of narcotics. Abrams et al. performed a small study that showed significant decreases in overall pain scores after the addition of vaporized cannabis.[57] More study is needed, but this combination may lead to lower doses of opioid treatment with fewer side effects. Cannabis has been shown to be safe (no one has ever died from an overdose) and not likely to cause dependence (thought to be equally addictive as caffeine).[58]

Although CBD and THC are the most popular known cannabinoids, other cannabinoids within the whole plant also have significant therapeutic properties, including cannabigerol (antitumor), cannabichromene (analgesic, anti-inflammatory, and antibiotic), and tetrahydrocannabivarin (although psychoactive, contains antidiabetic and anti-obesity properties). CBD alone (the nonpsychoactive cannabinoid) has been shown to reduce nausea, pain, and inhibit cancer growth on its own. Because CBD can be derived from hemp and not the cannabis plant itself, individuals in states that do not license medical marijuana who wish to try this option may have access to hemp-derived CBD products.[59]

Mood and Sleep

Mind Body Approaches for Mood and Sleep

Physical Activity: Yoga

A meta-analysis of 13 randomized, controlled trials of yoga in cancer survivors documented significant reductions in distress, anxiety, and depression; moderate reductions in fatigue; moderate increases in social and emotional function and QOL; and a small increase in functional well-being.[27]

Aromatherapy

An RCT of 15 days of inhaled lavender essential oil in 60 patients in an intensive care unit showed statistically significant increased quality of sleep and reduced level of anxiety in patients with coronary artery disease based on the Pittsburgh Sleep Quality Index (PSQI) and the Beck Anxiety Inventory (BAI) scale.[60] Another RCT compared a 4-week trial of blended essential oil (*Lavendula angustifolia, Salvia sclarea*, and *Origanum majoranava*) versus lavender essential oil versus acupressure massage versus placebo in 132 career women.[61] All treatment groups showed significant improvements in PSQI and Short Form 36 Health Survey (QOL) ($p < 0.05$), with the greatest benefit in the blended essential oil treatment group.

A meta-analysis of mindfulness-based therapy suggests it is moderately effective for improving anxiety and mood symptoms from pre- to post-treatment in an overall sample totaling 1,140 participants in 39 studies.[62] Importantly, these effects were maintained over follow-up and were found in populations including those with cancer, generalized anxiety, and chronic pain disorders. Mindfulness-based therapies have also been developed to support caregivers of palliative care patients, with promising improvements in mental distress and life satisfaction.[63]

Energy Medicine

Biofield therapies are based on the premise that each person has an endogenous biofield, which affects physiologic processes.[64] Biofield or energy therapies are purported to improve the balance of the biofield through the practitioner's gentle laying on of hands, placement of hands within the biofield, or distance-based healing.

Healing Touch (HT) is a biofield therapy endorsed by the American Holistic Nurses Association and the Canadian Holistic Nurses Association.[65] HT has the most standardized training, with an independent certification after completing five levels of training. A pilot study of HT found it to have positive effects on stress, fatigue, pain, and mood of patients with cancer.[66]

Reiki is a system of natural healing considered an energy medicine practice. Reiki is administered by the gentle laying of hands on top of or above a clothed individual so the Reiki practitioner can act as a conduit for energy to flow to needed areas in the recipient. One small study showed benefit in well-being, relaxation, pain relief, sleep quality, and reduced anxiety.[67] More study is needed as most RCTs have yielded inconclusive results.

Therapeutic Touch is another energy therapy based on the restoration of balance using a technique in which the hands are used to direct energy for healing purposes, usually without any direct physical contact. A Therapeutic Touch Program was introduced to a geriatric palliative care unit with treatments provided by volunteer Therapeutic Touch Practitioners.[68] A retrospective chart review suggests that implementation is feasible and appears to be safe and well-tolerated, with patients achieving a state of relaxation or sleep after treatment.

Acupuncture

Several RCTs and meta-analyses support acupuncture as both a beneficial monotherapy and as adjunct treatment, though others did not find evidence of efficacy.[69] The Canadian Network for Mood and Anxiety Treatments 2016 Clinical Guidelines for the Management of Adults with Major Depressive Disorder (MDD) rate acupuncture as a third-line treatment for patients with MDD.[69] Two systematic reviews and meta-analyses of auricular acupuncture and acupuncture with moxibustion for primary insomnia had positive results; however, the findings are limited by studies of poor methodological quality, insufficient sample size, and possible publication bias.[70,71]

Hypnosis

Hypnosis creates a state of "focused awareness and attention" during which the patient can be taught to undertake diversional thinking from unpleasant somatic experiences such as pain. One small study showed a select group of patients noted decreased anxiety and increased relaxation as a result of hypnosis.[72]

Natural Products for Mood and Sleep

Supplements and herbs commonly used for mood and sleep include S-adenosyl-L-methionine (SAMe), St. John's Wort, hydroxytryptophan (5HTP), and valerian.

SAMe

SAMe is a chemical found naturally in the body. SAMe is made in the body from methionine, an amino acid found in many proteins. It is known to help many of our cells function normally.[73] A meta-analysis of studies using SAMe in the treatment of depression showed favorable results.[74] SAMe also shows promise as an anti-inflammatory supplement used for pain relief in fibromyalgia.[75]

St. John's Wort

St. John's wort is a herb that is commonly used to treat depression. Many studies show that St. John's wort works as well as traditional antidepressants for the treatment of mild to moderate depression with fewer side effects. However, St. John's wort can react poorly with many medications and other supplements so drug–herb interactions should be checked before using.[76]

5HTP

5HTP is a serotonin precursor used to treat depression, fibromyalgia, migraines, insomnia, and tension headaches. While there is evidence that precursor loading may be of therapeutic value, particularly for the serotonin precursors 5-HTP and tryptophan, more studies of suitable design and size are needed for more conclusive results.[77]

Valerian Root

Valerian root is used primarily for insomnia, dyssomnia, and for anxiety-associated restlessness and sleeping disorders. It has also been used for many other conditions, but studies for these conditions are only preliminary in nature. A meta-analysis of 16 studies suggests that valerian might improve sleep quality without producing side effects.[78]

Melatonin

One well-known supplement used for sleep is melatonin. Orally, melatonin is used for jet lag, insomnia, shift-work disorder, circadian rhythm disorders in the blind, sleep–wake cycle disturbances, and nicotine and benzodiazepine withdrawal. Additionally, there are many studies using melatonin in combination with chemotherapeutic agents to promote cancer regression.[79]

Gastrointestinal Symptoms

Mind-Body Approaches for Gastrointestinal Symptoms

Acupuncture

The benefit of acupuncture for nausea and vomiting has been generally accepted for many years; the NIH Consensus Statement of 1997 supported acupuncture for adult postoperative and chemotherapy-related nausea and vomiting.[80] One point, the PC6 point (located 2½ to 3 fingerbreadths from the wrist crease up the arm), has the most convincing evidence, leading to FDA-approved wrist devices to provide acupressure at the PC6 point.[81–83] Acupuncture or acupressure that includes the PC6 point is a reasonable consideration for patients with persistent nausea and vomiting.

Hypnosis

Hypnosis is a psychotherapeutic technique performed by a trained clinician who uses therapeutic suggestions to produce changes in perception, cognition, affect, mood, behavior, and sensation that are mutually acceptable to the patient and provider.[84] Advanced practice nurses can receive training in hypnosis and can explore options through the Society for Clinical and Experimental Hypnosis and the American Society of Clinical Hypnosis. Hypnosis is a safe option for managing anticipatory nausea and vomiting for patients receiving chemotherapy. Patients can also be taught or can use audio versions of scripts for self-treatment.[85]

Progressive Muscle Relaxation and Guided Imagery

Progressive muscle relaxation (PMR) is a technique of alternately tensing and relaxing muscle groups in sequence throughout the body. Patients can do this on their own, but often will use a prerecorded script to guide the process. Guided imagery is often added to PMR to enhance mental visualization. The 2016 updated Multinational Association of Supportive Care in Cancer (MASCC)/European Society for Medical Oncology (ESMO) consensus recommendations for anticipatory nausea and vomiting in children and adults receiving chemotherapy confirmed their prior recommendation of progressive muscle relaxation training as a valuable therapy.[86]

Natural Products for Gastrointestinal Symptoms

Supplements and herbs specific for gastrointestinal concerns include glutamine, ginger, magnesium, and calendula.

L-Glutamine

L-glutamine is an amino acid found in high levels in the body. Although glutamine is traditionally classified as a nonessential amino acid, it is essential for maintaining intestinal function, especially during times of severe stress. L-glutamine is used for many conditions including diarrhea, HIV wasting, chemotherapy-induced mucositis, and for protection of immune and gut barrier function in people with esophageal cancer undergoing radiochemotherapy. Taking glutamine orally seems to enhance intestinal absorption of nutrients, decrease intestinal permeability, and increase weight gain in people with HIV/AIDS.[87] Research findings in chemotherapy-induced diarrhea have been inconsistent.[88,89]

Ginger

Ginger (*Zingiber officinale*) is a perennial plant grown in warmer climates. Its tuberous root is the source of the popular spice. Orally, ginger has been used for a host of conditions including motion sickness, diarrhea, dyspepsia, and anorexia, as well as nausea and vomiting. Topically, the fresh juice of ginger is used for treating thermal burns. The essential oil of ginger is used topically as an analgesic. Studies of ginger in treating antiretroviral-induced and chemotherapy-induced nausea and vomiting show promise.[90,91]

Magnesium

Magnesium is a mineral that is involved in more than 300 biochemical functions in the body. Most magnesium comes from dietary sources. There is some evidence that magnesium supplementation may enhance opioid-induced analgesia without increasing side effects and may also help with constipation.[92]

Calendula

Calendula (*C. officinalis*) is commonly known as pot marigold. Orally, it is used as an antispasmodic, to reduce fever, and for treating inflammation of the oral and pharyngeal mucosa. Clinically, Calendula mouthwash ameliorated the severity of radiotherapy-induced oral mucositis in patients with head and neck cancer.[93] As with most supplements, more study is needed.

Resources

Resources for Natural Products, Evidence, and Safety

It would likely be impossible to have knowledge about all herbs and supplements patients might be using, so it is helpful to have access to resources that could help in the understanding of indications for use, overall and comparative effectiveness, and potential side-effect profiles (Table 28.1).

Resources for Natural Products and Quality

In the United States, herbal medicines and dietary supplements are not subject to strict oversight by the FDA. In response to concerns about supplement quality, several third-party organizations now perform independent quality-control testing of actual products, providing information on whether supplements contain the stated ingredients and are free of contaminants. Consumer Lab, Natural Products Association, NSF International, and United States Pharmacopeia (USP) are several of the most prominent and commonly encountered organizations. Dietary supplements may have seals of approval from these organizations after successful testing. The website ConsumerLab.com is additionally an excellent resource available for a modest annual fee to help learn more about the supplements tested and recommended brands.

Resources for Deepening Knowledge about Integrative Medicine and Integrative Nursing

Learning about integrative nursing and health can be an enriching personal and professional experience. For many providers, it helps them reconnect to the reasons they pursued a career in healthcare in the first place. Learning can range from reading articles or online modules to conferences to degrees. Some examples of engaging courses are listed in Table 28.2.

Table 28.1 Resources: Natural products, evidence, and safety

Natural Medicines	https://naturalmedicines.therapeuticresearch.com/	Natural Medicines has several helpful point-of-care resources for the clinic setting including "Herb-Supplement Interaction," Medication Effectiveness," "Nutrient Depletion," and "Pregnancy-Lactation Checkers." The Clinical Management Series provides excellent diagnosis-based learning and monograph-based courses provide in-depth overviews of individual herbal medicines. Access to this resource is subscription-based: it is frequently included in hospital and health system libraries.
Memorial Sloan Kettering Cancer Center's About Herbs database	https://www.mskcc.org/cancer-care/diagnosis-treatment/symptom-management/integrative-medicine/herbs	A tool for the public as well as healthcare professionals with information on common herbs and other dietary supplements.

Table 28.2 Resources for deepening knowledge about integrative medicine and integrative nursing

Center for Spirituality & Healing: Integrative Nursing	https://www.csh.umn.edu/education/focus-areas/integrative-nursing	University of Minnesota offers the first Doctor of Nursing Practice (DNP) in Integrative Health and Healing and well as access to continuing education modules.
Center For Spirituality & Healing: Learning Modules	https://www.csh.umn.edu/education/online-modules-and-resources/learning-modules-healthcare-professionals	Online free modules offer an introduction to various topics in the field of complementary therapies. Each of the modules takes from 1 to 3.5 hours to complete and is organized into short sections. All modules feature content written by subject matter experts and reviewed by a faculty team from the schools of Nursing, Pharmacy and Medicine at the University of Minnesota.
American Holistic Nurses Association	http://www.ahna.org/	AHNA advocates for holistic nursing through continuing education, research, practice, networking, and advocacy.
Academy of Integrative Pain Management	https://integrativepainmanagement.site-ym.com/	AIPM mission: "To improve the lives of people with pain by advancing a person-centered, integrative model of pain care through evidence-guided education, credentialing, and advocacy that is now defined as 'best practice' in the National Pain Strategy published by NIH."
Osher Center for Integrative Medicine at Northwestern University	http://www.feinberg.northwestern.edu/sites/ocim/ http://ocim.nm.org/	The authors' location with websites highlighting clinical offerings, and an academic site with content for health professionals.
The Osher Collaborative for Integrative Medicine	https://www.oshercollaborative.org/	The Osher Collaborative for Integrative Medicine comprises an international group of six academic Centers at Harvard University, UCSF, Northwestern University, Vanderbilt University, University of Miami, and Karolinska Institute. The website provides links to resources from the programs.
National Center for Complementary and Integrative Health (NCCIH) is a National Institute of Health initiative	https://nccih.nih.gov/	NCCIH supports research and education in this evolving field. The website contains free online continuing medical education (CME), videocasts of the annual Distinguished Lecture Series, and databases for both clinical guidelines and systematic reviews.
Academic Consortium for Integrative Medicine & Health	https://www.imconsortium.org/	The mission of the Consortium is to advance integrative medicine and health through academic institutions and health systems. Many member institutions have clinical centers and education programs. Listings for members can be found on the site.
Academy of Integrative Health & Medicine	https://www.aihm.org/	An interprofessional association of integrative clinicians who embrace a person-centered, team-based approach to health care. AIHM provides transformational educational programs, connections to a global network, and resources and toolkits for our members.

Conclusion

CIM offers many more tools in the nurse's toolbox to deal with conditions and issues dealt with in palliative care. This chapter has only outlined in broad strokes some of the options available. Clinicians owe it to themselves and their patients to be aware, supportive, and even suggest some alternatives to conventional Western medicine. Embodying the principles of integrative nursing can bring connection and healing to the patient, the family, and, ultimately, to the caregiver.

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CHAPTER 29

Withdrawal of Invasive Mechanical Ventilation

Margaret L. Campbell

Key Points

- Mechanical ventilation can be withheld or withdrawn.
- Respiratory distress can be anticipated, assessed, and treated during withdrawal of invasive mechanical ventilation.
- Death follows ventilation withdrawal along varying trajectories characteristic of the patient's illness severity and dependence on other life-sustaining interventions, such as vasopressors.

Case Study: A Patient on Mechanical Ventilation

George, a 43-year-old man, presented to the emergency department with difficulty breathing secondary to streptococcal pneumonia. He required intubation, invasive mechanical ventilation, and admission to the MICU. His long MICU course with refractory pneumonia was complicated by deep venous thrombosis, pulmonary embolus, and witnessed cardiac arrest. He sustained anoxic encephalopathy and remained ventilator dependent with a tracheostomy. After discussion of his poor prognosis, his family made a decision with the MICU team to forgo further aggressive life-sustaining measures and to withdraw mechanical ventilation. The family was given the opportunity to remain at the bedside or wait in a private area during the withdrawal process.

George was not able to respond to commands but did withdraw from painful stimuli. Thus, it was presumed that he could experience distress. Further, he was ventilator-dependent and at high risk for developing respiratory distress during spontaneous breathing. For these reasons, he was premedicated with morphine 4 mg as an intravenous bolus with 1 mg of lorazepam. A rapid terminal weaning was undertaken in which oxygen and ventilation were reduced in step-wise fashion until George was breathing spontaneously. During the step-wise weaning he was monitored with the Respiratory Distress Observation Scale (RDOS). At each step, he was remedicated with morphine 4 mg if the RDOS score indicated the presence of respiratory distress. He required two bolus doses of morphine during the weaning process.

The ventilator was turned off and a humidified room air trach collar was placed. A continuous morphine infusion at 50% of the total bolus doses was initiated to maintain respiratory comfort. George died 4 hours after ventilator withdrawal.

Benefits and Burdens of Mechanical Ventilation

Mechanical ventilation has been used for decades to support breathing when patients experienced acute or chronic respiratory failure. Mechanical ventilation is of benefit when the patient, for a number of reasons, cannot maintain normal ventilation as evidenced by increasing carbon dioxide and respiratory acidosis; to treat these conditions, invasive and noninvasive modalities are employed. Invasive mechanical ventilation is accomplished after the establishment of an artificial airway, such as an endotracheal tube or tracheostomy. Noninvasive mechanical ventilation is applied over the nose or nose and mouth via a tight-fitting face mask. Examples of noninvasive mechanical ventilation include continuous positive airway pressure (CPAP) or bilevel positive airway pressure (BiPAP).

Invasive mechanical ventilation is employed after cardiopulmonary arrest, during general anesthesia, to treat respiratory failure that is not responsive to noninvasive ventilation, or for patients who are ventilator-dependent. Endotracheal intubation is used for periods of less than 2 weeks of ventilation; continued ventilation after 2 weeks is supported by tracheostomy. When respiratory failure occurs during an exacerbation of chronic pulmonary disease, noninvasive ventilation is often useful as a first response.[1] Patients with obstructive sleep apnea, chronic obstructive pulmonary disease (COPD), and amyotrophic lateral sclerosis (ALS) often use noninvasive ventilation at night or when breathing is difficult during the day.

Patients often experience discomfort during mechanical ventilation. With noninvasive modalities, the tight-fitting mask may produce generalized pressure-associated discomfort, feelings of suffocation, and pressure lesions on the bridge of the nose. Endotracheal intubation causes gagging, coughing, and drooling, and leaves the patient unable to verbalize because the tube passes through the vocal cords. In many cases of endotracheal intubation and some cases of noninvasive ventilation, the patient requires mechanical restraints or sedation to maintain the integrity of the life-saving treatment and to ensure ventilator synchrony.

Ventilator-dependent patients experience fewer burdens because they are routinely ventilated through a tracheostomy. Nonetheless, chronic ventilator dependence limits patient mobility and contributes to the development of immobility complications such as pressure ulcers, deep venous thrombosis, and pneumonia.

Ventilator withdrawal is considered as a treatment option when the treatment is more burdensome than beneficial, such as when the patient has a terminal illness or is unconscious or when the patient makes an informed, capable decision to cease treatment because her or his quality of life is poor. Ventilator withdrawal is conducted to allow a natural death free of tubes and machines.[2] In critical care units (adult, pediatric, and neonatal), ventilator withdrawal is usually undertaken because the patient is not expected to survive and/or to regain functional consciousness. Clinical standards, policies, and procedures about foregoing life-sustaining therapy, including mechanical ventilation, are in wide use and reflect broad agreement about the underlying principles regarding these decisions.[3]

Although withdrawal of ventilation occurs on a frequent basis across settings of care, there is little empiric evidence to guide the process. A review of the evidence to guide a ventilator withdrawal process demonstrated that small samples and largely retrospective chart reviews characterize the body of evidence about processes for ventilator withdrawal.[2] The cited research is not conclusive to make recommendations in all cases of ventilator withdrawal. However, a number of suggested processes may be useful in this clinical context, along with a team approach to the procedure and patient care to address anticipated symptoms.

Patients are ventilated because of respiratory failure and an inability to exchange respiratory gases without mechanical support. Dyspnea arises from increased inspiratory effort, hypercarbia, and/or hypoxemia; dyspnea is anticipated during and after ventilator withdrawal. Prevention and alleviation of dyspnea or respiratory distress becomes the focus of care during ventilator withdrawal. Some patients, if awake, may experience fear or anxiety before or during ventilator withdrawal, and this will require attention if present. Adult patients may experience barotrauma to the trachea from the pressure in the cuff, leading to laryngeal edema or spasm after extubation with development of post-extubation stridor.

Invasive Ventilator Withdrawal Processes

Advance Preparation

The Centers for Medicare and Medicaid Services has enacted guidelines for consistent processes around organ donation.[4] Hospital staff must notify their state Organ Procurement Organization (OPO) when decisions about ventilator withdrawal are being considered. The OPO will collaborate with the hospital staff to identify whether the patient is a donor candidate for donation after cardiac death and to seek consent from the next of kin. This evaluation by the OPO must be completed before ventilation is withdrawn. See Chapter 45 for more information regarding organ donation.

Timing to conduct the withdrawal process is generally negotiated with the patient's family and the healthcare team. This timing will depend on which team members will be present, including support personnel such as a chaplain. The time needs to be communicated to all clinical team members, and, ideally, the assigned nurse should have a reduced assignment to be able to spend one-on-one time with the patient and family.

Not all family members want to be present at the bedside during withdrawal. Another room nearby can be arranged with adequate seating, facial tissues, water, and access to a telephone. Religious observances or family-specific rituals need to be accommodated and completed before beginning the withdrawal process. Patient and/or family questions about what to expect can be addressed before beginning the process.[5] When ventilation is withdrawn from a small child, infant, or neonate, it is customary for a parent to hold the child on his or her lap during the process.

Neuromuscular blocking agents (NMBA), such as pancuronium or vecuronium, are being used with less frequency in the intensive care unit (ICU); when in use it is impossible to assess the patient's comfort. Thus, the NMBA should be discontinued with evidence of patient neuromuscular recovery before ventilator withdrawal is undertaken. In some cases, the duration of action of these agents is prolonged, such as when the patient has liver or renal failure and impaired clearance. Therefore, although controversial, withdrawal can proceed with careful attention to ensuring patient comfort if an unacceptable delay in withdrawing mechanical ventilation occurs because of protracted effects of NMBA.[6]

Measuring Distress

Dyspnea, also known as breathlessness, is a nociceptive phenomenon defined as "a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity. The experience derives from interactions among multiple physiological, psychological, social and environmental factors, and may induce secondary physiological and behavioral responses."[7] Dyspnea can be perceived and verified only by the person experiencing it. Many patients who are undergoing ventilator withdrawal are cognitively impaired or unconscious as a result of underlying neurological lesions or hemodynamic, metabolic, or respiratory dysfunction that produce cognitive impairment or unconsciousness. Respiratory distress is an observable (behavioral) corollary to dyspnea; the physical and emotional suffering that results from the experience of asphyxiation is characterized by behaviors that can be observed and measured.[8]

Most patients undergoing ventilator withdrawal will be unable to provide a self-report about any dyspnea experienced, particularly patients who are unconscious, severely cognitively impaired, or infants and neonates. Attempts to elicit a self-report should be made if the patient is conscious. Skill is required to detect nuances of behaviors, particularly when the patient is unable to validate the nurse's assessment. Initiation and escalation of sedatives and opioids should be guided by patient behaviors.

The RDOS is suitable for assessing the adult patient during the withdrawal of mechanical ventilation; reliability, validity, and intensity cut-points have been established.[8–10] This eight-variable categorical scale is the only known tool for assessing respiratory distress when the patient cannot self-report dyspnea, as typifies most patients undergoing ventilator withdrawal. Each variable is scored from 0–2 points and the points are summed. Scores range from 0 to 16: 0–2 = no distress, 3 signifies mild distress, 4–6 represents moderate distress, and scores of 7 or higher signify severe distress (Table 29.1). Infants and neonates often display nasal flaring, grunting at end-expiration, and sternal retraction.[11] Brain-dead patients by definition will not show distress, cough, gag, or breathe during or following ventilator withdrawal, and sedation or analgesia is not indicated.

Premedication for Anticipated Distress

As is the standard with pain management, opioids should be initiated to signs of distress and the advice to "start low and titrate slowly" is sage. For the opioid-naive adult, an initial intravenous

Table 29.1 Respiratory Distress Observation Scale

Variable	0 points	1 point	2 points	Total
Heart rate per minute	<90 beats	91–109 beats	≥110 beats	
Respiratory rate per minute	≤18 breaths	19–30 breaths	>30 breaths	
Restlessness: nonpurposeful movements	None	Occasional, slight movements	Frequent movements	
Accessory muscle use: rise in clavicle during inspiration	None	Slight rise	Pronounced rise	
Paradoxical breathing: abdomen moves in on inspiration	None		Present	
Grunting at end-expiration: guttural sound	None		Present	
Nasal flaring: involuntary movement of nares	None		Present	
Look of fear	None		Eyes wide open, facial muscles tense, brow furrowed, mouth open	
Total				

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bolus of 3–5 mg of morphine is recommended. Pediatric dosing is usually initiated at 0.05–0.1 mg/kg.[12] Anticipatory premedication is a sound practice if distress is already evident and if distress can be anticipated. There is no justification for medicating a brain-dead patient, and one could argue that the patient in a coma with only minimal brainstem function is also unlikely to experience distress. Doses that correspond to customary dosing for the treatment of dyspnea should guide dosing during ventilator withdrawal. Documentation of the signs of distress and rationale for dose escalation is important to ensure continuity across professional caregivers and to prevent overmedication and the appearance of hastening death. At the conclusion of the process, a continuous infusion may be initiated to maintain patient comfort; an infusion rate equivalent to 50% of the total amount of bolus medication is recommended. Thus, if the patient received three boluses of morphine at 5 mg (15 mg), the infusion would start at a rate of 7.5 mg/hr.

Weaning Method

Terminal extubation is characterized by ceasing ventilatory support and removing the endotracheal tube in one step. *Terminal weaning* is a process of stepwise, gradual reductions in oxygen and ventilation, terminating with placement of a t-piece or with extubation. In a pilot study, patients undergoing terminal extubation experienced more distress than patients with terminal weaning in an algorithmic, RDOS-guided approach.[13] Likewise, patients in the terminal extubation arm of a multisite comparison of extubation versus weaning were in more distress than those in the weaning arm.[14] Terminal extubation poses an abrupt change from supported ventilation to spontaneous ventilation in a fragile patient, likely contributing to the distress noted in these studies.

Rapid terminal weaning may afford the clinician the most control because it allows for careful, sequential adjustments to the ventilator with precise titration of medications to ensure patient comfort (Table 29.2).[13] Continuous patient monitoring with readily accessible opioids will afford the patient and family comfort regardless of method employed.

Extubation Considerations

Patients who are ventilator-dependent for 14 days or more are generally ventilated through a tracheostomy tube. After ventilator withdrawal, a tracheostomy collar with humidified room air or low-flow oxygen can be placed. Patients experiencing acute respiratory failure are ventilated through a nasal or oral endotracheal tube. Adult tubes have a cuff to maintain tube placement and occlude the trachea to prevent air leaking and loss of tidal volume; neonatal tubes are cuffless.

Removal of the endotracheal tube should be performed whenever possible because of patient comfort and the aesthetic appearance of the patient. However, in some cases airway compromise can be anticipated, such as when the patient has a swollen, protuberant tongue, or has no gag or cough reflexes. In cases of airway compromise, the disconcerting noises may be more distressing to the attendant family than the presence of the tube. Medication with dexamethasone may reduce airway edema permitting extubation when patients are at high risk for post-extubation laryngeal edema, but dosing would need to start 12 hours before withdrawal if the timing permits. A cuff-leak test entails measuring the volume of air loss when the endotracheal tube cuff is deflated prior to extubation. Air loss of less than 140 cc predicts post-extubation stridor.[15,16] Aerosolized racemic epinephrine is a useful intervention to reduce stridor after extubation.[16,17] Family counseling about usual noises that can be expected and that cause no distress should be done prior to extubation.[18]

Noninvasive Ventilator Withdrawal

Decisions to cease CPAP or BiPAP warrant a patient-centered approach similar to that used in the withdrawal of invasive mechanical ventilation. The number of process steps are fewer since there is no need to consider cuff-leak testing or extubation. Premedication for anticipated distress should be determined with the same criteria as with invasive mechanical ventilation. When the patient is comfortable, wean the FiO_2 by .20 every few minutes until room air level is reached (0.21). Turn off the pressure support and remove the mask. Medicate with morphine for reported dyspnea or displayed respiratory distress.

Ventilator Withdrawal at Home

Occasionally, a ventilator-dependent patient is cared for in the home or is transferred from hospital to home for ventilator withdrawal. The home setting for this procedure poses some significant

Table 29.2 Sample rapid wean

Process	Steps	Rationale
Planning	Cuff-leak testing	Affords prediction of post-extubation stridor.
Premedication: Patients able to experience distress (e.g., RASS +3 to −3)	Morphine 4 mg IV bolus	Morphine is effective for treating dyspnea. Comatose patients may not need premedication but should be monitored for distress development.
Weaning	1. Turn off PEEP 2. Wean FiO_2 by 0.2 every 1–2 minutes if no distress until FiO_2 = .21 (room air) 3. Change ventilator mode to SIMV at a rate of 10 with PSV at 5 cm. 4. Reduce SIMV rate by 2 breaths every 1–2 minutes if no distress until SIMV rate = 4. 5. Change ventilator mode to CPAP 0 PSV 5 cm 6. Turn off ventilator and remove from patient. 7. Extubate if cuff-leak test passed.	Step-wise weaning affords an opportunity to pause the process when distress develops. Patients are given the opportunity to "adjust" to each change rather than rapidly being changed from full ventilation to complete spontaneous breathing.
Assess distress	Measure RDOS at baseline and after every ventilator change.	Patients may develop respiratory distress anywhere along the trajectory from fully supported ventilation to spontaneous breathing.
Treat distress	Morphine 4 mg IV bolus whenever RDOS is ≥4.	RDOS 0–2 = no distress, 3 = mild distress.
Maintain comfort	Morphine infusion if patient needed medication during withdrawal and if predicted survival is more than minutes. Calculate the total morphine given during withdrawal as bolus doses. Begin infusion at a rate = 50% of total bolus doses. Titrate to maintain RDOS ≤3.	Patients may survive longer than minutes and can be triaged to a non-ICU bed. Nurse–patient ratios on non-ICU units do not afford frequent IV bolus dosing.
Treat stridor	Racemic epinephrine in 3 cc normal saline as an aerosol treatment. May need to be repeated ×1.	Opioids and benzodiazepines will not treat airway obstruction.

RASS, Richmond Agitation Severity Scale; PEEP, positive end-expiratory pressure; FiO_2, fraction of inspired air; SIMV, synchronized intermittent mandatory ventilation; CPAP, continuous positive airway pressure; RDOS, Respiratory Distress Observation Scale.

limitations if an intravenous access is not available, particularly if the patient is awake and aware. Awake, ventilator-dependent patients are at the highest risk of developing respiratory distress compared to patients with cognitive impairment or decreased consciousness. Respiratory distress can be treated with oral or subcutaneous morphine, however, the peak effect by these routes is longer than by the intravenous route, possibly posing a protracted interval for patient distress. An ideal home-based withdrawal should follow the same procedure as the ICU-based withdrawal with continuous nurse and respiratory therapist monitoring, immediate delivery of intravenous morphine to signs of respiratory distress, and the subsequent placement of a humidified trach collar after the ventilator is turned off. The intravenous access may be achieved by keeping the hospital line in place at discharge to afford use by the home care team. Alternatively, a peripheral line can be placed by the home care team.

A much slower weaning will need to be considered if an oral morphine is used. After each ventilator change, distress is measured. The weaning is paused when there is distress until the peak effect of morphine is achieved; this is as quick as 10 minutes intravenously and as long as 30 minutes by mouth. A terminal wean with an intravenous access generally occurs in 20–30 minutes, but a home-based withdrawal relying on oral or subcutaneous morphine may take a few hours.

Oxygen

A growing body of evidence suggests that oxygen is a useful palliative intervention to treat dyspnea when the patient is experiencing distress and is hypoxemic but offers no benefit when the patient has normal oxygenation.[19] Furthermore, when patients are near death and in no distress, oxygen is not necessary.[20] Thus, the patient can be cared for without oxygen following ventilator withdrawal unless there are signs of respiratory distress and hypoxemia. Nasal cannula is better tolerated than a face mask if oxygen is initiated.

Duration of Survival

Triage considerations after ventilator withdrawal may be guided by estimations of duration of survival. As expected, patients with the highest illness severity will die more quickly, particularly if they are also dependent on vasopressors or high levels of oxygen.[21,22]

Conclusion

Withdrawal of mechanical ventilation is a procedure that occurs with relative frequency. The benefits of this therapy, when initiated, is to replace failing lungs, extend life, and improve quality of life by relieving dyspnea associated with respiratory failure. When the burdens exceed the benefits, or when the patient is near death or unresponsive, decisions may be made to cease this therapy. Measures to palliate anticipated distress must be applied. A peaceful death after cessation of mechanical ventilation can be provided.

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SECTION III

Psychosocial and Spiritual Support

CHAPTER 30

The Meaning of Hope in the Dying

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Key Points

- Hope is a key factor in coping with and finding meaning in the experience of life-threatening illness.
- People with life-threatening illness and their families do not invariably lose hope; in fact, hope can increase at the end of life.
- Nurses can implement evidence-based practices to foster and sustain hope for patients and families at the end of life.
- Nurses need to understand and respect individual variations in hope processes to provide sensitive, effective care to patients and their families at the end of life.

Introduction

Emily Dickinson said: "Hope is the thing with feathers, That perches in the soul, And sings the tune without the words, And never stops—at all."[1] Classic writings have contemplated hope, extolling it as a virtue and an energy that brings life and joy.[2–4] Fromm[2] called hope "a psychic commitment to life and growth."

Despite its positive connotations, hope is intimately bound with loss and suffering. As the French philosopher Gabriel Marcel[3] observed, "Hope is situated within the framework of the trial." It is this paradox that manifests itself so fully at the end of life. Indeed, the critical role that hope plays in human life takes on special meaning as death nears. The ability to hope often is challenged, and it can elude patients and families during terminal illness. Hope for a cure is almost certainly destroyed, and even a prolonged reprieve from death is unlikely. Many patients and families experience multiple losses as they continue an illness trajectory that is marked by increasing disability and pain.

Even when hope appears to be strong within the dying person or the family, it can be problematic if hopefulness is perceived to be based on unrealistic ideas about the future.[5] Tension grows within relationships as people become absorbed in a struggle between competing versions of reality. Important issues may be left unresolved as individuals continue to deny the reality of impending death.

Despite these somber realities and the inevitable suffering, many people do maintain hope as they die, and families recover and find hope even within the experience of loss. How can this be? Part of the reason lies in the nature of hope itself—its resiliency and capacity to coexist with suffering. As witnesses to suffering and hope, palliative care nurses must understand these complexities and be confident and sensitive in their efforts to address hope and hopelessness in the people for whom they care.

To assist palliative care nurses, this chapter explores the many dimensions of hope and identifies its possible influence on health and quality of life (QOL). Nursing assessment and strategies to foster hope are described. In addition, specific issues such as "unrealistic hopefulness" and cultural considerations in the expression and maintenance of hope are discussed. The goals of the chapter are to provide the reader with an understanding about this complex but vital phenomenon, to offer guidance in the clinical application of this concept to palliative nursing care, and to explore some of the controversies about hope that challenge clinicians.

Definitions and Dimensions of Hope

Hope is an important concept for many disciplines, including philosophy, theology, psychology, nursing, and medicine. A classic nursing theory of hope, developed by Karin Dufault,[6] is particularly notable in its comprehensiveness. Dufault described hope as "a multidimensional, dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant." Dufault also theorized that hope has two interrelated spheres: particularized and generalized. *Particularized hope* is centered and dependent on specific, valued goals or hope objects. An example is the hope of a terminally ill patient to live long enough to celebrate a particular holiday or event. In contrast, *generalized hope* is a broader, nonspecific sense of a more positive future that is not directly related to a particular goal or desire. Dufault likened this sphere to an umbrella that creates a diffuse, positive glow on life.

Dufault postulated six dimensions of hope: affective, spiritual, relational, cognitive, behavioral, and contextual. The affective dimension of hope encompasses a myriad of emotions. Of course, hope is accompanied by many positive feelings, including joy, confidence, strength, and excitement. The full experience of hope, however, also includes uncertainty, fear, anger, suffering, and, sometimes, despair.[7] The philosopher Gabriel Marcel, for example, argued that, in its fullest sense, hope could only follow an experience of suffering or trial.[3] Marcel's thesis is corroborated by the experiences described by people with cancer who see their disease as "a wake-up call" that has opened their eyes to a greater appreciation for life and an opportunity for self-growth—in other words, an event that has forced them to confront their mortality while also inspiring hope.[8] The spiritual dimension is a central component of hope.[8,9] Hopefulness is associated with spiritual well-being,[9,10] and qualitative studies have shown that spirituality and spiritual practices provide a context in which to define hope and articulate hope-fostering activities.[11,12] These activities include religious beliefs and rituals but extend to broader conceptualizations of spirituality that encompass meaning and purpose in life, self-transcendence, and connectedness with a deity or other life-force.[13,14] Although spirituality is almost always viewed as a hope-fostering influence, serious illness and suffering can challenge one's belief and trust in a benevolent deity or be viewed as punishment from God; either interpretation of suffering can result in hopelessness.[15]

Relationships with significant others are another important dimension of hope. Interconnectedness with others is cited as a source of hope in virtually every study, and physical and psychological isolation from others is a frequent threat to hope.[16,17] Hope levels are positively associated with social support.[18,19] In addition to family members and friends, nurses offer patients a unique and independent source of support for hope.[20,21] Harris et al.[16] reported that HIV peer-counseling relationships inspired hope in both the counseling recipients and their counselors. Despite being vital sources of hope, other people can threaten a patient's hope by distancing themselves from the patient, showing disrespect, discounting the patient's experiences, disclosing negative information, or withholding information.[20,22]

The cognitive dimension of hope encompasses many intellectual strategies, particularly those involving specific goals that require planning and effort to attain. Identifying goals can motivate and energize people, thereby increasing hope.[16,22] When identifying goals, people assess what they desire and value within a context of what is realistically possible.[23] They appraise the resources necessary to accomplish their goals against the resources that are available to them. They then take action to secure the resources or meet the goals, and they decide on a reasonable time frame in which to accomplish the goals.[24] Active involvement in one's situation and attainment of goals increases the sense of personal control and self-efficacy, which, in turn, increases hope.[23] If a person repeatedly fails to attain valued goals, hopelessness and negative emotions, such as anxiety, depression, or anger can result.[22]

The behavioral, goal-focused thoughts and activities that foster hope are similar to the problem-focused coping strategies originally described by Lazarus and Folkman.[25] This similarity is not surprising because hope is strongly associated with coping.[26] Hope has been identified as a foundation or mediator for successful coping, a method of coping, and an outcome of successful coping.[26,27] Many strategies that people use to maintain hope have been previously identified as coping methods, and models of maintaining hope overlap substantially with models of coping.[26] Strategies to maintain hope include problem-focused coping methods (e.g., setting goals, actively managing symptoms, getting one's affairs in order), emotion-focused strategies (e.g., using distraction techniques, appraising the illness in nonthreatening ways), and psychosocial processes (reminiscing, leaving a legacy, positive reappraisal, motivating processes).[26,28,29]

Contextual dimensions of hope are the life circumstances and abilities that influence hope—for example, physical health, financial stability, and functional and cognitive abilities. Common threats to hope include acute, chronic, and terminal illness; cognitive decline; fatigue; pain; and impaired functional status.[26,28] These factors, particularly physical illness and impairment, do not inevitably decrease hope if people are able to overcome the threat through cognitive, spiritual, relational, or other strategies.

Influence of Hope and Hopelessness on Adaptation to Illness

Hope influences health and adaptation to illness. Empirical evidence indicates that diminished hope is associated with poorer QOL,[27] persistence of suicidal ideation,[30] and higher incidence of suicide.[31] Hopelessness also increases the likelihood that people will consider physician-assisted death as an option for themselves.[32] Hopelessness is significant in the etiology and maintenance of depression.[31]

In addition to its influence on psychological states and behaviors, there is some evidence to suggest that hope affects physical states as well. Researchers have found associations between hopelessness and early markers of endothelial dysfunction, a precursor to atherosclerosis.[33] Rawdin and colleagues[34] reported that hope was associated with the psychosocial elements of the pain experience.

Variations in Hope among Different Populations

The preceding description of hope is derived from studies involving diverse populations, including children and older adults. In addition, research has been conducted in inpatient, outpatient, and community settings with well persons and those with a variety of chronic and life-threatening illnesses. The experiences of families also have been described. Over these diverse populations and settings, many core concepts have been identified that transcend specific groups. However, some subtle but important differences exist. For this reason, hopefulness in selected populations is addressed in the following sections.

Hope in Children and Their Parents

A few investigators have examined hope in children and their parents. Lotz and colleagues[35] studied pediatric advance care planning (ACP) in bereaved parents. The findings suggested that holding onto hope is important and should be directly addressed in ACP conversations in order to elicit realistic hopes and make meaningful plans.

Salmon and colleagues[36] explored how hope arose in interactions between oncologists and parents of children aged 1–12 years with acute lymphoblastic leukemia. The investigators found an interpersonal basis of hope (e.g., most parents linked their ability to hope to "having faith in" the oncologist and consistently valued oncologists' explicit positivity) and a psychological basis of hope (e.g., focusing on short-term events associated with treatment and avoiding information about the longer term).

In another study, van der Geest and colleagues[37] surveyed parents of children who died with cancer to evaluate relationships between parents' sources of coping and the impact of faith and hope for a cure on parents' long-term adjustment. Neither faith nor strengthening of faith were associated with less long-term traumatic grief or symptoms of depression, and remaining hopeful for a cure was not related to increased levels of traumatic grief or symptoms of depression.

Hope and Older Adults

Numerous studies have examined hope in ill and healthy older adults.[38–40] Findings from these studies suggest that certain hope-related themes and factors take on special significance for this age group. For example, in a recent metasynthesis of qualitative research, hope was described as an important psychological resource that helped older adults deal with chronic illness.[39] Older adults used two interrelated processes to help deal with their experience: (1) transcendence, a process of reaching inwardly and outwardly, and finding meaning and purpose; and (2) positive reappraisal, a recognition and acknowledgment that their situation had changed and they could see positive possibilities for the future. Although chronic illness that impairs physical functioning is linked with decreased hope, diagnosis of a life-threatening disease, such as cancer, is not associated with low levels of hope.[41] This finding may reflect an attitude among older adults that the QOL that remains matters more than the quantity.

Hirsch and colleagues[38] studied older adults recruited from primary care settings. They found that functional impairment was associated with increased depressive symptoms, and individuals with higher levels of hope experienced fewer depressive symptoms. Also, the ability to generate goals and resources to accomplish goals contributed to higher levels of hope.

Among younger European American adults, hope tends to be tied to being productive; personal and professional achievements figure prominently in one's ability to nurture and maintain hope. In contrast, older adults are more likely to focus on spirituality, relationships, leaving a legacy focused on others, finding meaning and purpose, and other factors that are not linked with accomplishment.[39] Hope-fostering activities include reminiscing, adjustment to transitions and losses, spirituality, and relationships with others.[29,39]

Hope from the Family Caregiver's Perspective

Family caregivers are an integral component in palliative care. Patients and families influence each other's hope, and nursing interventions must focus on both groups. Often, the physical and psychological demands placed on family caregivers are great, as are threats to hope.[12,28,42] Threats to hope in caregivers include isolation from support networks; questioning of one's spiritual beliefs; concurrent losses, including loss of significant others, health, and income; and inability to control the patient's symptoms. Kellas and colleagues[43] found that difficulties in communicating with healthcare providers, such as communicating misleading information or "false hope," prevented family caregivers' transition from particularized to generalized hope. Other studies found that hope played a significant role in family caregivers' perception of increased strain and overall QOL.[44,45]

Strategies to maintain hope in family caregivers are similar to those found in patients, with a few differences. Spending time with others in the support network is very important for caregivers. In addition, being able to reprioritize demands helps caregivers conserve much-needed energy. Toussaint and colleagues[46] found that the relationship between self-forgiveness and hope was twice the size for caregivers of patients with cancer, as compared to patients. Encouraging self-forgiveness may be important to promote hope and unburden self-blame.

Case Study: Mr. R, Hope in a Spiritual Person

At 68 years old, Mr. R presented to the hospital with progressive abdominal distention over 4 weeks. His past medical history included hypertension, type 2 diabetes, and depression. Imaging revealed large-volume ascites, omental caking, and peritoneal carcinomatosis. Over the course of the next month, he went through an army of diagnostic tests, all of which pointed to cancer, none of which revealed the primary source. During his hospitalization, his sister died and he was unable to attend the funeral due to weakness and continued need for frequent paracenteses. Mr. R's spirituality was central to his being. It was helping him cope with the death of his sister and his new illness. He was hoping to "live a normal life" after treatment. He defined "normal" as going to church, walking independently, and driving the church van to pick up fellow parishioners. Mr. R was also hoping for a cure. He told the palliative care nurse practitioner, "I have to remain positive. I have faith that if there is a cure, then I will be cured."

As Mr. R remained in the hospital, he continued to wait for a diagnosis. He struggled with the unknown and processed everything that was going on with his body. He wished he could go home for "just one day, to go to church on Sunday." When the oncologists began to favor lymphoma as a primary cancer, they began high-dose steroids. When his ascites persisted, they placed a peritoneal drain. The drain was the first visible sign of cancer for Mr. R. Clinically, he was worsening and the shape of his hope began to change. On a visit with the palliative care team, just 2 months after his symptoms began, he said the following:

> I know what I have to do. I want to be home and with my family. I fought the fight and I ran the race. Now I have to let the Lord have his way. Lord, let be what will be. Lord let me go, if that is your will. Whatever good I have left, let me do it wonderfully. Don't get me wrong, I'm scared of dying but I will find peace. There are many things that I have to say to people that I have not yet said. I wish that more people could know my heart . . .

As Mr. R's illness progressed, he began to hope for something new. At the beginning of his cancer journey, he hoped for normalcy and for a cure. Now he hoped for peace, to be with his family, to follow God's will, and to continue his generativity to others. Mr. R also hoped to go home with hospice care on a Saturday so he could buy a new suit and surprise everyone at church on Sunday.

Clearly, Mr. R expressed some complex abstract hopes for the time he had left; he also described tangible accomplishable hopes for the near future.

Hope in Terminally Ill Patients: Is Hope Compatible with Death?

Research demonstrates that many people are able to maintain hope during acute and chronic illness. Hope also can thrive during the terminal phase of an illness, despite the realization that no cure is possible. In qualitative and mixed-method studies, hope was maintained regardless of the severity of disease or the proximity to death.[10]

Although hope levels may not decrease, the nature of hope often is altered through the dying process. Other changes in hope at the end of life include an increased focus on relationships and trusting in others, as well as a desire to leave a legacy and to be well-remembered.[10,28] Spirituality also increases in importance for some patients during the terminal phases of illness.[28] People also adopt specific strategies to foster hope at the end of life.[10] Many of these approaches are summarized in Box 30.1.

Box 30.1 Sources of Hope/Hope-Fostering Strategies in Terminally Ill Adults

- Love of family and friends
- Spirituality/having faith
- Setting goals and maintaining independence
- Positive relationships with professional caregivers
- Humor
- Personal characteristics
- Uplifting memories

Although hope tends to change in people with terminal illness, maintaining a delicate balance between acceptance of death and hope for a cure often remains an important task up until the time of death, even when people acknowledge that cure is virtually impossible.[47,48] The dying person also needs to envision future moments of happiness, fulfillment, and connection.[10]

Case Study: A Patient Highlighting Cultural Differences

Mr. N was an 84-year-old active man who was working around his house one Wednesday morning when he began to have some slurred speech. His wife noticed his change in speech and wanted to call their sons. Mr. N insisted it would pass and agreed to rest on the couch. A few hours later, he began to experience right arm and leg numbness. His wife was alarmed and called her eldest son, who then called 911.

Mr. N was brought to the hospital and imaging confirmed a left internal carotid artery occlusion, believed to be cardioembolic. He underwent thrombectomy with a postoperative course complicated by encephalopathy and nonconvulsive status epilepticus. A week later, repeat imaging revealed new multifocal right acute ischemic infarcts.

Throughout the course of his hospital stay, Mr. N's wife and two adult sons were updated on his progress. Multiple family meetings were held where neurologists painted the picture of a poor prognosis. His son said, "I know that my father will never walk again, talk again, or eat again. I only hope that he can open his eyes again and recognize my mom's voice." Mr. N's son explained that his father had experienced many struggles in his life and they felt that he could recover, despite the odds.

Mr. N was born in China and lost his parents at the age of 9. He worked hard and immigrated to the United States in the 1980s with his wife. They made a life for themselves in Philadelphia. He became a licensed contractor, and they raised two sons. He was a stubborn man and overcame much adversity. His family said they would accept if he died naturally, but they struggled with actively withdrawing any form of life support when there was even a minor chance that he could wake up. Mr. N's family struggled with the sudden onset of his debility and hoped that he might retain the basic faculties of hearing and voice recognition.

Multicultural Views of Hope

Over the past three decades, understanding of the clinical phenomenon of hope has increased dramatically through theoretical discourse and empirical investigation. Although knowledge regarding the components, processes, and outcomes of hope has grown dramatically, progress in multicultural research on hope has been limited. The samples in many studies that examine hope or hopelessness are ethnically homogeneous,[34,49,50] or their ethnic composition is unknown.[24.44] The studies that do include ethnically diverse samples are small,[51,52] precluding any comparisons or generalization of findings.

Several excellent European studies have contributed greatly to the general understanding of hope.[24,36] However, many of these investigations use frameworks and instruments developed by US researchers whose work is founded on homogeneous samples. Moreover, it may be that hopefulness for Europeans is more similar to that of middle-class Americans than it is different.[28]

Farone and colleagues[53] examined the associations among locus of control, negative affect, hope, and self-reported health in 109 older Mexican American women with cancer. They found that hope and internal locus of control both showed significant associations with better health outcomes. Although these findings are similar to those for white, non-Hispanic samples, the authors cautioned that they were unable to explore the characteristics of control that may be unique to Latina populations. They recommended that future research include attribution of control based on religious beliefs and the concept of *fatalismo* (fatalism).

Despite the growing body of research in diverse samples, existing research may not adequately reflect the experience of hope for people from non-European cultures. Several known cultural differences could certainly limit the applicability of current conceptualizations of hope, especially within the palliative care context. Three issues that theoretically could have a major impact on multicultural views of hope are time orientation, truth-telling, and one's beliefs about control.

Time orientation is identified as a cultural phenomenon that varies among cultural groups. Some cultural groups, usually highly individualistic ones, are future-oriented. Within these groups, people prefer to look ahead, make short- and long-term plans, and organize their schedules to meet goals.[54] Because hope is defined as being future-oriented, with hopeful people more likely to identify and take action to meet goals, members of these future-oriented cultures may possibly appear more hopeful than people who are predominantly present-focused. On the other hand, people who are more focused on the present may be better able to sustain hope at the end of life, when the ability to create long-range goals is hindered by the uncertainty surrounding a terminal diagnosis. Additional research is needed to clarify these relationships.

The value for *truth-telling* in Western healthcare systems also may affect hope. Current ethical and legal standards require full disclosure of all relevant healthcare information to patients.[55] Informed consent and patient autonomy in medical decision-making, two eminent values in American healthcare, are impossible without this disclosure.[55] Although few would advocate lying to patients, truth-telling is not universally viewed as helpful or desirable.[56,57] In some cultures, it is believed that patients should be protected from burdensome information that could threaten hope. Truthful, but blunt, communication may also be seen as rude and disrespectful in some cultures, and the feeling of being devalued and disrespected has a negative impact on hope. In addition to the threats to hope that frank discussion is believed to engender, people who prefer non-disclosure of threatening information may be seen as attempting to cling to unrealistic hopes by refusing to listen to discouraging facts about their condition.

A third cultural concept that may affect hope is one's feeling of being in *control*. As described earlier, control is a core attribute in many conceptualizations of hope. Although control can be relinquished to others, including healthcare providers or a transcendent power, personal control often is central to the hoping process. In Euro-American cultures, applying one's will and energy to alter the course of an illness or to direct the dying process seems natural and desirable. Advance directives are one culturally sanctioned way in which members of these societies exert control over the dying process.[58] However, this desire for and belief in personal control is not a common feature in many other cultures. In cultures where death is viewed as part of the inherent harmony of living and dying, attempts to exert any influence over the dying process may seem unnatural or inappropriate.[58] People from diverse cultures who take a more passive role in their healthcare, or who do not espouse a desire to control their illness or the dying process, may be viewed as less hopeful than people who manifest a "fighting spirit" and active stance.

More research is needed to test theories of hope in multicultural groups, both to ensure the appropriate application of current conceptualizations to diverse cultural groups and to develop new theories that are relevant for these groups. Until this work is done, palliative care clinicians must be cautious in applying current hope theories and sensitive to the possible variations in diverse populations.

Models of Maintaining Hope for People with Life-Threatening Illnesses

Many investigators have identified factors that foster hope and strategies that enable people to sustain hope despite life-threatening or chronic illness. Although there is considerable concordance across these studies regarding many of the major themes, various models emphasize different styles and strategies that demonstrate the diversity in hope-fostering approaches.

As described previously, many people with terminal illness turn to activities and coping strategies that cultivate generalized hope rather than an emphasis on achievement and control. These strategies reflect a sense of peace and acceptance of death and center on "being" rather than "doing." These strategies are described in Box 30.1.

In contrast, Olsson and colleagues[28] found that patients preserved their hope using two goal-oriented or problem-solving processes: (1) maintaining life and (2) preparing for death. The patients tried to maintain life in several ways, by keeping up with their day-to-day tasks and hobbies; communicating with others about practical matters and emotional feelings; involving other people such as family, friends, or professionals; and actively searching elsewhere for something to give them hope. To prepare for death, patients took responsibility for planning their own funerals and other practical matters and arranged things so that family would have less of a burden. People use multiple strategies that allow them to confront and to avoid the negative aspects of illness and death. Although the strategies used to manage the threat of death often seem to predominate, these activities occur within a background of recognition and acknowledgment of the possibility of death. This process of negotiating between acknowledgment and management of these fears has been identified in other studies of people with life-threatening illnesses.[59]

Although some people continue to search for a cure after receiving a terminal diagnosis, hoping for a cure can coexist with awareness of death and engagement with life's activities.[29,47] Most people eventually accept their prognosis and mourn the loss of their original goals. At this point, they need to develop and pursue alternative goals that are possible in light of their diminished physical function, end-of-life symptoms, and loss of energy.

These different approaches for maintaining hope are important to describe and understand because they assist the palliative care nurse in designing effective strategies to foster hope. They increase clinicians' awareness regarding the various ways that people respond to chronic and terminal illness, and they guide clinicians in their interactions with patients and families to sustain hope. They also help palliative care providers understand difficult or troubling responses, such as unrealistic hopefulness.

The Issue of "Unrealistic" Hopefulness

Reality surveillance is a feature of many conceptualizations of hope. Often, clinicians, researchers, and theorists believe that mentally healthy people should choose and work toward realistic goals. In these frameworks, adhering to unrealistic hopes or denying reality is a sign of maladaptive cognitions that could lead to negative health outcomes.

Clinical examples of unrealistic hopes that cause consternation are numerous and diverse. For instance, one patient with advanced cancer might hope that his persistent severe sciatica is from exercise and overuse rather than spinal metastases. The nurse working with this patient may continually contradict his theory, asserting that his denial of the probable malignant cause of the pain will delay effective treatment. Another patient might insist that a new cure for her illness is imminent, causing distress for the nurse, who believes that the patient's unrealistic hopes will hinder acceptance of and preparation for death.

Despite these concerns, however, some investigators argue that the nurses' fears may be unfounded. This perspective is based on more recent studies that have led researchers to question the view that denial and unrealistic hopes are maladaptive. Instead, they argue that to believe these patients' professions of hope are unrealistic is to challenge or negate the legitimacy of the dominant depiction of the promise and potential cure provided by medical science.[60,61]

In addition to promoting positive outcomes, "unrealistic" hopes need to be assessed within the context of uncertainty. For instance, people frequently respond to dire prognostic news with the observation that they can always "beat the odds." Given that no one can predict the future with absolute certainty, it is impossible to predict which individuals with a 2% chance of remission or recovery will actually be cured. So, if a person hopes for something in the future that appears highly unlikely, can it be known for certain that it will not occur? Patients and families often need to focus on this uncertainty to sustain hope.[59] Research supports the idea that patients' and families' hopes and goals are effective coping strategies, even when the likelihood of obtaining them seems remote.[45]

Olsman and colleagues[60] conducted an interpretative synthesis of the literature showing that nurses and physicians could take three perspectives on hope of palliative care patients: (1) realistic perspective, (2) functional perspective, and (3) narrative perspective. Hope is viewed from a realistic perspective when hope is truthful and focused on adjusting hope to the truth. From a functional perspective, hope helps patients cope with treatments or face uncertainty. Nurses who take a narrative perspective focus on meaning that is valuable to patients. They also suggested that clinicians can take more than one perspective at the same time.

Assessing Hope

As in all nursing care, thorough assessment of physical and psychosocial factors must precede thoughtful planning and implementation of therapeutic strategies. Therefore, consistent and comprehensive evaluations of hope should be included in the palliative nursing assessment. Some conceptual elements of hope, such as those focusing on meaning and purpose in life, are included in a spiritual assessment. Rarely, however, are comprehensive guides to assessing hope included in standardized nursing assessment forms. In Table 30.1, examples of questions and probes can be used to assess hope.

Like pain, hope is a subjective experience, and assessment should focus on self-report. However, behavioral cues can also provide information regarding a person's state of hope or hopelessness. Hopelessness is a central feature of depression; therefore, behaviors such as social withdrawal, flat affect, alcohol and substance abuse, insomnia, and passivity may indicate hopelessness.

As discussed earlier, the patient's terminal illness affects the hope of family caregivers, who, in turn, influence the hope of the

Table 30.1 Guidelines for the clinical assessment of hope in palliative care

Interview question/probe	Rationale
Illness understanding	
1. What is your understanding of what's happened to you and the probable course of your illness?	Explore the person's perceptions of seriousness of his or her illness, and possible future
2. How hopeful are you right now, and how does your illness affect your sense of hope?	Determine the person's general sense of hope and the effect of the terminal illness on hope
Caregivers	
1. Who provides you with emotional, physical, and spiritual support?	Identify people that provide support and enhance hope
2. Who are you most likely to confide in when you have a problem or concern?	Identify others in whom the person has trust
3. What kinds of difficult experiences have you and your family/caregivers had to deal with in the past? How did everyone cope with those experiences?	Explore experiences of coping with stressful situations
4. What kinds of things do family, support people, and healthcare providers do that make you more hopeful? Less hopeful?	Identify specific behaviors that affect hope and recognize that other people can also decrease hope
Sources of meaning and purpose	
1. What gives you hope?	Identify relationships, beliefs, and activities that provide a sense of purpose and contribute positively to hope
2. What helps you make sense of your situation right now?	Identify the ways in which the person makes meaning of difficult situations
3. Do you have spiritual or religious practices or support people who help you? If yes, what are these practices or people?	Identify if and how spirituality acts as a source of hope
4. Has your illness caused you to question your spiritual beliefs? If yes, how?	Terminal illness can threaten the person's basic beliefs and test one's faith
5. How can we help you maintain these practices and personal connections with spiritual support people?	Identify ways in which clinicians and others can support spiritual practices that enhance hope
Quality of life	
1. How would you rate your overall quality of life (excellent, good, fair, or poor), and why?	Assess the person's perceptions and threats to quality of life
2. What do I need to know about you as a person to give you the best care possible?	Explore what is important to the person, and possible sources of hope
Coping with the illness	
1. How are you coping with this illness?	Gain insight into the ways the person is coping
2. Where do you find the strength to face your illness?	Explore the person's spiritual, religious, and existential values
3. How well are you able to cope with the symptoms of your illness? How do these symptoms affect your hope?	Uncontrolled end-of-life symptoms have been found to negatively influence hope
Sources of hope over time	
1. In the past, what or who has made you hopeful?	Identify sources of hope from the person's past that may continue to provide hope during the terminal phase
2. Right now who and what provides you with hope?	Identify current sources of hope
3. What do you hope for in the future?	Assess generalized and specific hopes for the future

Source: From References 67, 68: Rosenblatt L, Meyer FL. Psychosocial issues in advanced illness. *UpToDate*. May 9, 2017; and Okon TR. Overview of comprehensive patient assessment in palliative care. *UpToDate*. June 26, 2017.

Table 30.2 Descriptions of selected instruments to measure hope and hopelessness

Instrument name	Brief description
Beck Hopelessness Scale	20-item, true-false format Based on Stotland's definition of hopelessness: system of negative expectancies concerning oneself and one's future Developed to assess psychopathological levels of hopelessness; correlates highly with attempted and actual suicide
Herth Hope Index	12-item, 4-point Likert scale; total score is sum of all items; range of scores 12–48 Designed for healthy and ill populations Assesses three overlapping dimensions: (1) cognitive-temporal, (2) affective-behavioral, (3) affiliative-behavioral Spanish, Thai, Chinese, Swedish translations available
Hopefulness Scale for Adolescents (Hinds)	24-item visual analog scale Assesses the degree of the adolescent's positive future orientation Tested in several populations of adolescents; healthy, substance use disorders, emotional and mental health problems, cancer
Miller Hope Scale	40-item scale, 5-point Likert scale Assesses 10 elements: (1) mutuality/affiliation, (2) avoidance of absolutizing, (3) sense of the possible, (4) psychological well-being and coping, (5) achieving goals, (6) purpose and meaning in life, (7) reality surveillance–optimism, (8) mental and physical activation, (9) anticipation, (10) freedom Chinese, Swedish translations available
Snyder Hope Scale	12-item, 4-point Likert scale Based on Stotland's definition of hope; focus is on goals identification and achievement Tested in healthy adults, adults with psychiatric illness, children

patients. Therefore, the hope of the patient's family caregivers and other significant support people also should be assessed.

Over the past decades, researchers from several disciplines have developed instruments to measure hope and hopelessness. The theoretical and empirical literature documents the comprehensiveness and face validity of these tools. Advances in psychometric theory and methods have allowed the evaluation of multiple dimensions of validity and reliability. The development and use of well-designed and well-tested tools has contributed greatly to the science of hope. Although a thorough discussion of these measures is beyond the scope of this chapter, Table 30.2 provides a brief description of several widely used and tested instruments.

Nursing Interventions to Maintain Hope at End of Life

Clinicians, theorists, and researchers recognize that nurses play an important role in instilling, maintaining, and restoring hope in the people for whom they care. Researchers have identified many ways in which nurses assist patients and families to sustain hope in the face of life-threatening illness. Box 30.2 provides a summary of nursing interventions to instill hope. A brief perusal of this table

Box 30.2 Nursing Interventions to Foster Hope

Experiential Processes

- Prevent and manage end-of-life symptoms
- Use lightheartedness and humor appropriately
- Encourage the patient and family to transcend their current situation
- Encourage aesthetic experiences
- Encourage engagement in creative and joyous endeavors
- Suggest literature, movies, and art that are uplifting and highlight the joy in life
- Encourage reminiscing
- Assist patient and family to focus on present and past joys
- Share positive, hope-inspiring stories
- Support patient and family in positive self-talk

Spiritual/Transcendent Processes

- Facilitate participation in religious rituals and spiritual practices
- Make necessary referrals to clergy and other spiritual support people
- Assist the patient and family in finding meaning in the current situation
- Assist the patient/family to keep a journal
- Suggest literature, movies, and art that explore the meaning of suffering

Relational Processes

- Minimize patient and family isolation
- Establish and maintain an open relationship
- Affirm patients' and families' sense of self-worth
- Recognize and reinforce the reciprocal nature of hopefulness between patient and support system
- Provide time for relationships (especially important in institutional settings)
- Foster attachment ideation by assisting the patient to identify significant others and then to reflect on personal characteristics and experiences that endear the significant other to the patient
- Communicate one's own sense of hopefulness

Rational Thought Processes

- Assist patient and family to establish, obtain, and revise goals without imposing one's own agenda
- Assist in identifying available and needed resources to meet goals
- Assist in procuring needed resources; assist with breaking larger goals into smaller steps to increase feelings of success
- Provide accurate information regarding patient's condition and treatment in a skillful and sensitive manner
- Help patient and family identify past successes
- Increase patients' and families' sense of control when possible

reveals an important point about these strategies: for the most part, nursing care to maintain patients' and families' hope fundamentally is about providing excellent physical, psychosocial, and spiritual palliative care. There are few unique interventions to maintain hope, and yet there is much nurses can do. Because hope is inextricably connected to virtually all facets of the illness experience—including physical pain, coping, anxiety, and spirituality—improvement or deterioration in one area has repercussions in other areas. Attending to these relationships reminds clinicians that virtually every action they take can influence hope, negatively or positively.

Another vital observation about hope-inspiring strategies is that many approaches begin with the patient and family. The experience of hope is a personal one, defined and determined by the hoping person. Although others greatly influence that experience, ultimately the meanings and effects of words and actions are determined by the person experiencing hope or hopelessness. Many approaches used by people with life-threatening illness to maintain hope are strategies initiated with little influence from others. For example, some people pray; others distract themselves with television watching, conversation, or hobbies (i.e., knitting); and many patients use cognitive strategies, such as minimizing negative thoughts, identifying personal strengths, and focusing on the positive. For many patients and families, careful observation and active support of an individual's established strategies to maintain hope will be most successful.

Family caregivers and other support people should be included in these approaches. Ample evidence demonstrates that patients and people within their support systems reciprocally influence one another's hope. In addition, family and significant others are always incorporated into the palliative care plan and considered part of the unit of care. Maintenance of hope also is a goal after death, in that hope-restoring and -maintaining strategies must be an integral part of bereavement counseling.[62]

Specific Interventions

The framework for the following discussion encompasses the major themes found in the literature, and, although they are not mutually exclusive, they provide a useful organizing device. This section also includes a brief discussion of ways in which nurses need to explore and understand their own hopes and values in order to provide palliative care that fosters hope in others.

Experiential Process Interventions

The experiential process of hope involves the acknowledgment and acceptance of suffering while at the same time using the imagination to move beyond the suffering and find hope.[10] Included in these types of strategies are methods to decrease physical suffering and cognitive strategies aimed at managing the threat of the terminal illness.

Uncontrolled symptoms, such as pain, fatigue, dyspnea, and anxiety, cause suffering and challenge the hopefulness of patients and caregivers. Timely and adept symptom prevention and management is central to maintaining hope. In home-care settings, teaching patients and families the knowledge and skills to manage symptoms confidently and competently also is essential.

Other ways to help people find hope in suffering is to provide them a cognitive reprieve from their situation. One powerful strategy to achieve this temporary suspension is through humor. Humor helps put things in perspective and frees the self, at least momentarily, from the onerous burden of illness and suffering. Making light of a grim situation brings a sense of control over one's response to the situation, even when one has little influence over it. Of course, the use of humor with patients and families requires sensitivity as well as a sense of timing. The nurse should take cues from the patient and family, observe how they use humor to dispel stress, and let them take the lead in joking about threatening information and events. In general, humor should be focused on oneself or on events outside the immediate concerns of the patient and family.

Other ways to move people cognitively beyond their suffering is to assist them in identifying and enjoying that which is joyful in life. Engagement in aesthetic experiences, such as watching movies or listening to music that is uplifting, can enable people to transcend their suffering. Sharing one's own hope-inspiring stories also can help.

Another strategy is to support people in their own positive self-talk. Often people naturally cope with stress by comparing themselves with people they perceive to be less fortunate or by identifying attributes of personal strength that help them find hope.[63] For example, an elderly, married woman with advanced breast cancer may comment that, despite the seriousness of her disease, she feels luckier than another woman with the same disease who is younger or without social support. By comparing herself with less fortunate others, she can take solace in recognizing that "things could be worse." Similarly, a person can maintain hope by focusing on particular talents or previous accomplishments that indicate an ability to cope with illness. People may also cite their high level of motivation as a reason to feel hopeful about the future. Acknowledgment and validation of these attributes supports hope and affirms self-worth for patients and families.

Spiritual Process Interventions

Several specific strategies can foster hope while incorporating spirituality. These strategies include providing opportunities for the expression of spiritual beliefs and arranging for involvement in religious rituals and spiritual practices.

Assisting patients and families to explore and make meaning of their trials and suffering is another useful approach. Encouraging patients and families to keep a journal of thoughts and feelings can help people in this process. Suggesting books, films, or art that focuses on religious or existential understanding and transcendence of suffering is another effective way to help people make sense of illness and death.

Palliative care nurses also should assess for signs of spiritual distress and make appropriate referrals to spiritual care providers and other professionals with expertise in counseling during spiritual and existential crises.

Relational Process Interventions

To maximize hope, nurses should establish and maintain an open relationship with patients and members of their support network, taking the time to learn what their priorities and needs are and then addressing those needs in timely, effective ways. Demonstrating respect and interest and being available to listen and be with people—that is, affirming each person's worth—is essential.

Fostering and sustaining connectedness among the patient, family, and friends can be accomplished by providing time for uninterrupted interactions, which is especially important in institutional settings. Nurses can increase hope by enlisting help from others to help achieve goals. For example, recruiting friends or arranging for a volunteer to transport an ill person to purchase a gift for a grandchild can cultivate hope for everyone involved. It is important to help others realize how vital they are in sustaining a person's hope.

Rational Thought Process Interventions

The rational thought process is the dimension of hope that specifically focuses on goals, resources, personal control and self-efficacy, and action. Interventions related to this dimension include assisting patients and families in devising and attaining goals. Providing accurate and timely information about the patient's condition and treatment helps patients and families decide which goals are achievable. At times, gentle assistance with monitoring and acknowledging negative possibilities helps the patient and family to choose realistic goals. Helping to identify and procure the resources necessary to meet goals also is important.

Often, major goals need to be broken into smaller, shorter term achievements. For example, a patient with painful, metastatic lung cancer might want to attend a family event that is 2 weeks away. The successful achievement of this goal depends on many factors, including adequate pain control, transportation, and ability to transfer to and from a wheelchair. By breaking the larger goal into several smaller ones, the person is able to identify all the necessary steps and resources. Supporting patients and families to identify those areas of life and death in which they do have real influence can increase self-esteem and self-efficacy, thereby instilling hope. It also helps to review their previous successes in attaining important goals.

This domain also includes ways in which clinicians balance the need to communicate "bad news" while sustaining patients' and families' hope. The difficulties inherent in delivering negative information to patients and families does not release us from our duty to communicate openly and honestly; however, it does require that palliative care nurses and other clinicians communicate skillfully in ways that assist patients and families to sustain hope. There are many articles describing empirically derived methods for delivering bad news sensitively and communicating in ways that maintain hope.[52,64]

Programs to Enhance Hopefulness

In addition to discrete actions that individual nurses take to foster hope, several investigators have developed and tested programs to enhance hope in people with life-threatening illness.

Duggleby and colleagues[29] evaluated the effectiveness of the Living with Hope Program (LWHP), a brief intervention designed for older adults with advanced cancer receiving home-based palliative care services. Grounded in their earlier research,[21] the LWHP is a 1-week intervention consisting of a visit from a trained assistant, a copy of the film "Living with Hope," and a choice of one of three hope-focused activities. The investigators found that LWHP participants used four psychosocial processes (reminiscing, leaving a legacy, positive reappraisal, and motivating processes) while participating in the intervention that fostered hope.

Rustøen and colleagues[24] studied the effects of a professional-led group intervention on hope and psychological distress in a community-based sample of cancer patients. The intervention consisted of eight 2-hour sessions focused on belief in oneself and in one's ability, emotional reactions, relationships with others, active involvement, spiritual beliefs and values, and acknowledgment that there is a future. The results showed increased hope levels and decreased psychological distress immediately following the intervention; however, this was not sustained at the 3- and 12-month assessments. The investigators suggested that, like other cognitive-behavioral interventions, additional "booster sessions" would have been helpful.

Hall and colleagues[65] conducted a randomized controlled trial to assess the ability of dignity therapy to reduce distress in advanced cancer patients. The intervention was comprised of an interview with a therapist in which the patient discussed the most important aspects of their life and their legacy or advice to family and friends they most want to be remembered. The interview was tape-recorded, transcribed, and edited into a document, which the patient could share with family and friends. Levels of hope and self-reported benefits were higher in the intervention group at 1- and 4-week follow-up, as compared to the control group.

Ensuring the Self-Knowledge Necessary to Provide Palliative Care

Providing holistic palliative care requires a broad range of skills. Astute management of physical symptoms and a solid command of technical skills must be matched with an ability to provide psychosocial and spiritual care for patients and families at a time of great vulnerability. To nurture these latter skills, nurses should continually reflect on and evaluate their own hopes, beliefs, and biases and identify how these factors influence their care. In an intriguing study, investigators examined the relationship between nurses' hope and their comfort in caring for and communicating with dying children and their families. They found that, after controlling for the number of years in nursing, nurses' hope and hours of palliative care education both were significantly associated with comfort in caring for dying children and their families.[66] These findings underscore the importance of education and self-reflection in delivering compassionate, skilled palliative care. In providing high-quality care, nurses also should evaluate how they are affected by patients' and families' responses and strategies to maintain hope. For example, does it anger or frustrate the nurse that the patient seems to refuse to acknowledge that his or her disease is incurable? Is this anger communicated nonverbally or verbally to the patient or family? In addition to self-reflection, it is important for palliative care nurses to remain hopeful while working with dying patients by engaging in self-care activities.

Conclusion

Hope is central to the human experience of living and dying, and it is integrally entwined with spiritual and psychosocial well-being. Although terminal illness can challenge and even temporarily diminish hope, the dying process does not inevitably bring despair. The human spirit, manifesting its creativity and resiliency, can forge new and deeper hopes at the end of life. Palliative care nurses play important roles in supporting patients and families with this process by providing expert physical, psychosocial, and spiritual care. Sensitive, skillful attention to maintaining hope can enhance QOL and contribute significantly to a "good death" as defined by the patient and family. Fostering hope is a primary means by which palliative care nurses accompany patients and families on the journey through terminal illness.

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CHAPTER 31

Bereavement

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Key Points

- "Bereavement" is the state of having experienced the death of a significant other.
- "Loss" is a generic term indicating the permanent absence of a current or future possession or relationship.
- "Mourning" encompasses the death rituals engaged in by the bereaved.
- "Grief" is an emotional response to loss.

Bereavement

With the pronouncement of death, those who have the closest blood or legal connections to the deceased are considered *bereaved* in a given society. Bereavement confers a special status on the individual, entailing both obligations and special rights. The obligations concern disposition of the body and any attendant ceremonies, as well as disposal of the worldly goods of the deceased unless indicated otherwise in a legal document such as a last will and testament. The rights include dispensation from worldly activities such as work and, to a lesser degree, family roles for variable periods of time. Bereavement entails loss, grief, and recovery, and associated processes.[2] Before an expanded discussion of bereavement is undertaken, it is important to distinguish the concept of bereavement from such related terms as "loss," "mourning," and "grief."

Loss

"Loss" is a generic term that signifies absence of an object, position, ability, or attribute. More recently, it also has been applied to the death of a person or pet. Absence or loss of the same entity has different implications depending on the strength of the relationship with the owner. For example, loss of a dog with which there was an indifferent relationship results in less emotional disruption for the owner than the loss of a dog that was cherished. The term often is applied to the death of an individual, and it is the bereaved person who experiences the loss. That is not to say that friends and colleagues don't also feel a sense of loss with the death of a cherished friend or colleague or even an admired political or entertainment figure. When a loss occurs, its meaning is determined by the person(s) who sustained the loss. The attributes of loss can be formulated as follows:

- Loss in this context signifies the permanent absence of a given relationship or possession.
- Each loss is valued differently and ranges from no or little value to great value.
- The meaning of the loss is determined primarily by the individual sustaining it.

This suggests that it is wiser not to make assumptions about loss, but to query further as to its meaning to the individual.

Mourning

Mourning has been described in various ways. Kagawa-Singer[3] described mourning as the social customs and cultural practices that follow a death. This definition captures the social construct of mourning practices and the obligation of the bereaved to engage in these practices, such as participation in the customary rituals appropriate to membership in a given group. These rituals and behaviors acknowledge that a loss has occurred for the individual and the group and that the individual and the group are adjusting their relationships so as to move forward without the presence of the deceased individual.

Mourning is also expressed in the symbolism entailed in funerals and burials. Burial grounds contain the expressions of what was considered appropriate in each time period for the memorialization of the deceased. These memorials may be above or below ground, in cemeteries or memorial parks, as part of individual graves or mausoleums, or be various permutations of these. The availability of space for burials influences the manner in which burials and memorials are constructed. Bachelor examines the various reasons for a visit to cemeteries by mourners, including to fulfill obligations, to help achieve independence from the deceased, and to seek solace.[4](p. 408)

Grief

Grief is the response to the loss of a person, pet, or object with which there was an emotional attachment. As Stroebe and Boerner[5] note, grief is a "normal, emotional reaction to the loss of a loved person and not a psychiatric disorder."(p. 576) Nonetheless, the process of grief has been studied and reformulated, phases identified, types proposed (anticipatory, complicated, disenfranchised), and expressions of grief described. Given that nurses work largely with individuals and families, but in some cases also with communities, several sections of this chapter focus on grief as it relates to these different entities.

The Process of Bereavement

Bereavement takes many forms. It is influenced significantly by culture. In Victorian times, bereaved women in the northeastern United States wore black for a year and used black-edged stationery, while men wore a black armband for a matter of days before resuming their regular activities. Bereavement is also guided by religious practice, the nature of the relationship with the deceased, the age of the deceased, and the manner of death. For example, the impact of the additional factor of refugee status for an émigré Muslim widow living in Denmark is reflected in the story of her experience.[6] This epitomizes the multiple factors that affect the bereavement experience. Changes have occurred in what is considered "appropriate" for those who are bereaved. The wearing of black by a widow ("widow's weeds") for the remainder of her life and the presumption that grief will be "resolved" within a year are no longer societal or professional expectations.

Routine bereavement care involving a check-in with the bereaved can be helpful in identifying people at risk for complicated grieving. Situations in which individuals are expected to "get on with it" may pose difficulties for those who are bereaved. Individuals who have demanding work responsibilities may not receive the support required as a result of the need to remain productive. For individuals who are unable to avail themselves of face-to-face support groups, whether for reasons of time, distance, or responsibilities, an Internet support group may be an option. Pector[7] provides a host of such online resources. Given that the best therapy is prevention, palliative care teams who identify caregivers at risk for bereavement maladjustment can intervene early to prevent long-term difficulties.

Aside from such proactive approaches for all bereaved persons, Sheldon[8] reported the following predisposing factors for a poor bereavement outcome: ambivalent or dependent relationship; multiple prior bereavements; previous mental illness, especially depression; and low self-esteem. Other predisposing factors for poor bereavement outcomes include sudden and unexpected death, untimely death of a young person, lack of preparation for the death, stigmatized deaths (e.g., AIDS, suicide, culpable death), sex of the bereaved person (e.g., elderly male widower), caring for the deceased person for more than 6 months, and inability to carry out valued religious rituals.[8]

A nationwide study in Denmark found that those bereaved by spousal suicide had higher risks of developing mental and physical disorders (cirrhosis; sleep disorders) than the general population.[9] Furthermore, there were higher risks of mental disorders, suicidal behaviors, and mortality compared with spouses bereaved by causes other than suicide. Boyle, Feng, and Raab[10] note that widowhood increases the risk of death regardless of the type of death of the spouse. They observe that the risk of mortality is increased 10–40% for the surviving spouse.

In addition to the professional caregiver's gut feeling that this relative will not do well, other predictive factors of poor outcomes include level of perceived social support, hardiness, lack of opportunities for new interests, and stress from other life crises, as well as dysfunctional behaviors and attitudes appearing early in the bereavement period, consumption of alcohol and drugs, smoking, and morbid guilt.[8,10] Other poor outcomes, in a study conducted in Ireland, included the patient dying in a hospital (when that was not their choice), a relative stopping work to care for the dying person, being a close relative, and lower socioeconomic status.[11] Those who remained employed and in cases where the dying person had no preference as to place of death experienced better bereavement outcomes.

Another consideration that has an impact on bereavement is the caregiving demand on the family. The contributions of family members to providing care at home include personal care, preparation of food and drink, illness-related care (symptom management, appointments), shopping, and other tasks. In a national study conducted of cancer caregivers, it was found that the mean number of hours per week spent in such activities was almost 95 hours with a median of 69.5 hours.[12] This time expenditure exceeds the 24.5 hours previously reported. These demands can place a significant strain on the family and may have an impact on the bereavement experience, depending on how the caregiving experience is viewed by the caregiver and the family. In another study of caregivers and bereavement, there was no difference with regard to gender as to caregiver demographic characteristics other than a difference between younger and older spousal caregivers.[13] Younger widows and widowers experienced greater unmet social needs and were less likely to be able to "move on" with their lives.

Wartime bereavement has its own set of challenges. With the death of a service member, the spouse and children contend not only with the grief attending to the death of a loved one but may also lose their military base or other housing provided to them as service member families. The wife or husband also loses his or her role as a military spouse.[1] The importance of practical support for the bereaved is underscored whether they are military or civilian.[1,14]

Mental distress prior to bereavement, such as depression and anxiety, as well as a high level of perceived burden with lack of support, was predictive of a poor bereavement outcome.[15] Knowledge of and alertness to such predisposing factors are useful for the provision of help, both lay and professional, early in the course of the bereavement and even prior to bereavement so as to prevent further debilitating events for caregivers. In addition to social support, healthcare policy, such as paid time off for family illness or a bereavement leave, can have a profound effect on the experience of bereavement as part of the context in which care is provided.[16]

Mourning

O'Gorman contrasted death rituals in England with those in Ireland. She recalled the "Protestant hushed respectfulness which had somehow infiltrated and taken over a Catholic community."[17](p. 1133) The body was taken from the home by the funeral director. Children continued with school and stayed with relatives; they were shielded from the death. By way of contrast, in an Irish wake, "The body, laid out by a member of the family in order to receive a 'special blessing,' would be in the parlour of a country house surrounded by flowers from the garden and lighted candles."(p. 1133) The children, along with the adult members of the family, viewed the corpse. "When visitors had paid their 'last respects' they would join the crowd in the kitchen, who would then spend all night recounting stories associated with the dead person."(p. 1133) O'Gorman noted the plentiful availability of alcohol and stated, "by the end of the night, to the uninitiated the event would appear to be more like a party than a melancholy event."(p. 1133) Although O'Gorman initially found this distasteful, she "now believes that rituals like the Irish wake celebrate death as a happy occasion and bestow grace upon those leaving life and upon a community of those who mourn them."(p. 1133)

The Irish wake, like the reception held in a church basement, hall, restaurant, or private home, serves not only for the expression of condolences but also as an opportunity to reinforce the connections of the community. Anyone familiar with such events knows that a variety of social and business arrangements are made by mourners both within and outside the immediate family. And although some gatherings are more reserved and others lustier, giving the deceased a good send-off ("good" being defined by the group) is central to each. The good send-off is part of the function of the funeral as a transitional rite—that is, as a means of atoning for the sins of the mortal being and as preparation for life in the afterworld. The value of the Irish wake, which in the United States may look more like the Protestant burial O'Gorman[17] describes, is the time spent together sharing stories and feelings.

In the United States, funeral services are held not only in religious establishments such as churches or synagogues, but also in funeral homes. These services, frequently under the aegis of a clergyperson, may also be conducted by a staff member of the funeral home. More recently, these services have also taken on the earmarks of a memorial service, accompanied by pictures of the deceased and the bereaved and remarks by selected close family members and friends of the deceased.

With the Irish wake as practiced in Ireland, one is not alone with one's feelings but in the company of others who are devoting the time to mourning (integration). This devotion of time to mourning is also found in the Jewish religion, where the bereaved "sit shiva," usually for 7 days.[18] In Judaism, the assumption is that the bereaved are to focus on their loss and the grieving of that loss. They are to pay no attention to worldly considerations. This period of time of exemption from customary roles may facilitate the process. Certainly, having a "minion," in which 10 men and women (10 men for Orthodox Jews) say prayers each evening, reinforces the reality of the death and the separation. For the Orthodox, the mourning period is 1 year.

A very different pattern of mourning is practiced by the Hopi of Arizona. The Hopi have a brief ceremony with the purpose of completing the funeral as quickly as possible so as to get back to customary activities.[19] The fear of death and the dead, and of spirits, induces distancing by the Hopi from nonliving phenomena. Stroebe and Stroebe[19] contrasted Shinto and Buddhist mourners in Japan with the Hopi. Both Shinto and Buddhist mourners practice ancestor worship; as a result, the bereaved can keep contact with the deceased, who become ancestors. Speaking to ancestors as well as offering food is accepted practice. In contrast to this Japanese practice, what occurs in the United States is that those bereaved who speak with a deceased person do so quietly, hiding the fact from others, believing others will consider it suspect or pathological. It is, however, a common occurrence. As mentioned previously, bringing food to the ancestor or (e.g., to celebrate the Day of the Dead) to the cemetery is part of the mourning practice in Hispanic and many other societies. These practices have many functions, including signifying respect for the deceased and providing a mechanism for the expression of feelings by the bereaved.

Practices, however, change with time, although one can often find the imprint of earlier rituals. The practice of saving a lock of hair or the footprint of a deceased newborn may have evolved from the practice in Victorian times of using hair for mourning brooches and lockets. Today, virtual or online memorials take the form of personal web pages in a study by Mitchell and colleagues, who suggest that "virtual memorials blur the boundaries between the living and the dead."[20(p. 426)] The authors posit, "Virtual memorials may even imply a kind of ethereal techno-presence whereby the ideal of heaven is being reconfigured as technologically mediated space/time: a digital set of pearly gates."[20(p. 428)] These mourning practices of virtual memorials provide continuing bonds with the deceased and offer a clue to the answer to the question posed for the last section of this chapter: When is it over? Before addressing this question, another needs to be raised and that is the question of support and an assessment of the type of support required. One such assessment is the Bereavement Common Assessment Framework.[21] This framework examines "Client and Family Factors, Caring and Death Experience, and Environmental Factors."[(p. 679)] As Blackburn and colleagues state:

> If palliative care services are to more fully address needs in bereavement, this necessitates a person-in-environment, individualized client-centered and holistic bereavement support program that encompasses experiences of the death, interpersonal and intra-psychic factors and situational and environmental factors.[21(p. 680)]

The Nature of Grief

Rubin and Schecter conceptualized bereavement-related grief into the two-track model of bereavement as a means of understanding and addressing the bereavement process and its outcome.[22] Track 1 addresses biopsychological functioning and is concerned with two questions: (1) "Where are the difficulties in biopsychological functioning?" (2) "Where are the strengths and growth manifest?" Track 2 examines the relationship to the deceased and focuses on two questions: (1) "What is the state of the desire to reconnect with the deceased affectively and cognitively?" (2) "What is the nature of the ongoing relationship to the deceased? Is the death story integrated?" In essence, bereavement involves adjusting to a world without the physical, psychological, and social presence of the deceased. Li and Chen used the dual-process model to examine social support as encompassing the emotional, instrumental and informational spheres.[23] Stroebe and Schut added the important concept of "overload" as it applies to "activities, events, experiences, and other stimuli."[24(p. 100)] What is important here is the inclusion of everyday life stressors as affecting both "loss oriented" and "restoration oriented" coping. Fasse and Zech (2016) also address the impact of everyday activities as an additional stressor.[25]

The death of a spouse/partner shortly after bereavement has been shown to be more likely to occur in elderly persons within the first 3 months after the death of their loved one.[26] Cardiovascular events are also more likely to occur, especially within the first 30 days following bereavement[27] but are manifested differently in people with cardiovascular disease (CVD). In women with CVD, bereavement was associated with decreased mortality as compared with married women, whereas widowed men with CVD experienced higher mortality than married men with CVD.[28] The researchers account for this in the elimination of the stress of caregiving for the wives. In addition, Stahl and colleagues found no "significant interaction between depressive symptoms and bereavement."[28(p. 702)]

The distinction between grief and depression in the bereaved is an important one. As Middleton and colleagues[29] concluded, "The bereaved can experience considerable pain and yet be coping adaptively, and they can fulfill many depressive criteria yet at the same time be experiencing phenomena that are not depressive in nature." Even in individuals with a history of "sadness or irritability" before bereavement, although they may have more intense expressions of grief, the rate of recovery is the same as for those without such a history.[30] Fried and colleagues (2015) assert that their analysis reveals the complexity of the relationship between bereavement and depression and conclude that bereavement most likely engenders loneliness.[31] Other authors are not as sanguine and caution that subsyndromal symptomatic depressions are "frequently seen complications of bereavement that may be chronic and often are associated with substantial morbidity."[32] For example, more intense grief with an increasing risk of depression was identified in the caregivers of middle-aged cancer patients.[33] Furthermore, in Korea, using a nationally representative sample, there was a relatively high prevalence of both anxiety (48%) and depressive symptoms (57.6%) in family caregivers, 2–6 months post bereavement.[34] Being the spouse, and the younger age of the deceased and the spouse were associated with increased risk of both anxiety and depression.[34] It should be noted that the first 6 months and especially the period from 1 to 6 months post bereavement are the most challenging for many bereaved individuals. The debates about the nature of depression and grief in bereavement have taken on new relevance given the publication of the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition (DSM-5),[35] discussed later in this chapter.

Various theorists have developed a series of stages and phases of grief work. The most well-known to the general public are those stages formulated by Elizabeth Kübler-Ross. Proposed for those facing a death, these stages have also been applied to those experiencing a loss. Kübler-Ross[36] identified five stages: denial and isolation, anger, bargaining, depression, and acceptance. The commonality among all theorists of the stages of grief is that the individual moves through (1) notification and shock, (2) experience of the loss emotionally and cognitively, and (3) reintegration. Based on these stages, Corr and Doka[37] proposed the following tasks:

1. To share acknowledgment of the reality of death.
2. To share in the process of working through the pain of grief.
3. To reorganize the family system.
4. To restructure the family's relationship with the deceased and to reinvest in other relationships and life pursuits.

With regard to the last task, some dispute has arisen concerning the degree to which separation from the deceased must occur. Klass and colleagues[38] make the compelling argument that such bonds continue. They opine that "survivors hold the deceased in loving memory for long periods, often forever" and that maintaining an inner representation of the deceased is normal rather than abnormal. Winston's study of African American grandmothers demonstrates that they maintained strong bonds with the deceased.[39]

The second area of dissension is the expectation that intense grief must be resolved within 2 weeks. More will be said later in the chapter about the changes in the time frame for the so-called *bereavement exclusion* for a diagnosis of major depressive disorder.

A third area of discussion concerns whether the concept of recovery, or some other term, best connotes what occurs after coming to terms with a death and getting on with one's life.[40,41] It has been suggested that "recovery" is a term more appropriate to an illness and that death is a normal process of life. Balk,[42] however, argues for a term that incorporates the potential for transformative growth.

A fourth area of debate is the issue of the medicalization of the grief process. Given that death is a normal part of the cycle of living, grief, too, is considered a normal process. As shall be observed in the following sections of this chapter, grief, although considered normal, may also become "complicated." As such, interventions may be needed. A medical diagnosis provides legitimacy to those engaged in the treatment encounter, including funding for those who are engaged in providing treatment.

A fifth area of vigorous discussion concerns the efficacy of grief counseling. Larson and Hoyt[43] provide a compelling argument about the efficacy of grief counseling and that the negative view of grief counseling's value is unfounded. The question of continuing bonds and the length of the grief process are addressed again at the close of this chapter. Readers are invited to consider all of these questions in light of their own experiences and readings of the literature. In this next section, types of grief are examined.

Types of Grief

The types of grief examined in this section are not exhaustive of all types of grief, but rather encompass the major categories. Different terms such as "common grief" and "chronic grief" may be used for some of these same phenomena.

Anticipatory Grief

Anticipatory grief shares similarities with other forms of grief. The onset may be associated with the receipt of bad news. Anticipatory grief must be distinguished from the concept of *forewarning*. An example of forewarning is learning of a terminal diagnosis. Anticipatory grief is an unconscious process, whereas forewarning is a conscious process. With forewarning of a terminal diagnosis, the question is, "What if we do?" With a death, that question becomes, "What if we had done?" With the former question, there is the potential for hope; with the latter query, there may be guilt.

Even with forewarning, preparation for loss may not occur, given that this may be perceived as a betrayal of the terminally ill person. There also have been instances of family members unconsciously preparing for the death of an individual and going through the grieving process only to have that person recover to find no place in the lives of his or her loved ones. This is an example of anticipatory grief.

Whether forewarning of death is helpful is dependent on how the time is used. If it is used to make some preparation for role change, such as becoming familiar with the intricacies of the role the terminally ill person plays in the family (e.g., mastering a checking account or other financial responsibilities of the family), such time may be used to the benefit of all concerned. On the other hand, anticipatory grieving resulting in reinvestment of emotional energy before the death of the terminally ill person is detrimental to the relationship.

Family members and friends are "warned" when their loved one is diagnosed with certain disease entities such as cancer with metastases. If the primary problem is Alzheimer's disease, there may be a long decline in which, ultimately, familiar figures are no longer recognized. In either situation, the death of the ill person may be experienced both with sadness and with a sense of relief that the caregiving burden is no more. The price of that relief is that the patient is no more.

The sense of relief experienced by caregivers is often a source of guilt feelings about wishing the patient dead. It is important to clarify for the family member or significant other that feelings of relief in being freed of the caregiver burden are not equivalent to wishing someone dead. A woman who experienced relief from not having to care for her bulky husband was assisted to examine this distinction and, consequently, was able to grieve uncomplicated by feelings of guilt. For other individuals, the concern is about what one did or didn't do prior to their loved one's death or guilt about once again feeling happy even though they are now bereaved.[44] Furthermore, persons who have cared for a dying person may experience a sense of accomplishment, knowing that they have done everything they could for their loved one. Research results on what makes an individual resilient after spousal loss include continued participation in everyday activities and in social relationships and the expectation that the survivor would receive comfort when needed.[45] In the following section, anticipatory grief is contrasted with what is termed "uncomplicated grief."

Uncomplicated Grief

In uncomplicated grief, an individual in a normal emotional state experiences a loss that causes a reaction and an emotional low; subsequently, the individual begins to recover to his or her former state. This process of recovery is occasioned by brief periods of relapse, but not to the depths experienced previously. Ultimately, the individual moves to adjustment to the loss. Although this description simplifies the turmoil that may be experienced, discussion of expressions of grief later in this chapter capture the physical, psychological, behavioral, and social upset that characterizes even uncomplicated grief.

Niemeyer[46] offered a new perspective by focusing on meaning reconstruction. He developed a set of propositions to capture adaptation to loss:

1. Death as an event can validate or invalidate the constructions that form the basis on which we live, or it may stand as a novel experience for which we have no constructions.
2. Grief is a personal process, one that is idiosyncratic, intimate, and inextricable from our sense of who we are.
3. Grieving is something we do, not something that is done to us.
4. Grieving is the act of affirming or reconstructing a personal world of meaning that has been challenged by loss.
5. Feelings have functions and should be understood as signals of the state of our meaning-making efforts.
6. We construct and reconstruct our identities as survivors of loss in negotiations with others.

Niemeyer[46] viewed meaning reconstruction as the central process of grief. The inability to make meaning may lead to complications.

Complicated or Prolonged Grief

Complicated and prolonged grief are terms for a prolonged, intense response to bereavement.[47(p. 652)] Researchers have identified the diagnostic criteria for complicated grief disorder. These criteria include "the current experience (>1 year after a loss) of intensive, intrusive thoughts, pangs of severe emotion, distressing yearnings, feeling excessively alone and empty, excessively avoiding tasks reminiscent of the deceased, unusual sleep disturbances, and maladaptive levels of loss of interest in personal activities."[48]

Other researchers have underscored the need for the specification of complicated grief as a unique disorder and have developed an inventory of complicated grief to measure maladaptive symptoms of loss.[49] The Inventory of Complicated Grief is composed of 19 items with responses ranging from "Never" to "Rarely," "Sometimes," "Often," and "Always." Examples of items include, "I think about this person so much that it's hard for me to do the things I usually do"; "Ever since she (or he) died it is hard for me to trust people"; "I feel that it is unfair that I should live when this person died"; and "I feel lonely a great deal of the time ever since she (or he) died."[49] This inventory may be helpful to healthcare practitioners because it differentiates between complicated grief and depression.[48] Finally, it is the severity of symptomatology and the duration that distinguishes abnormal and complicated responses to bereavement.[50]

The Inventory of Complicated Grief was used by Ott[51] with 112 bereaved participants in a study in which those identified as experiencing complicated grief were compared with those who were not. Those with complicated grief both identified more life stressors and felt they had less social support than the other bereaved individuals in the study. Lack of preparation for the death of a loved one has also been associated with complicated grief and depression.[52] The perspective of complicated grief as a stress response syndrome has been explicated by Shear and colleagues.[53] It is important to observe that the characteristics of complicated grief have not been found to vary by race or by the violence of the loss.[54,55]

It should be noted that there is some concern among professionals that what is a normal process is being transformed into a medical condition by healthcare practitioners. Complicated grief, however, may require professional intervention.[43,56] Approaches to therapy have included cognitive-behavioral therapy, presented face-to-face as well as over the Internet, and supportive counseling.[56] Bearing this in mind, disenfranchised grief poses different but potentially related problems.

Disenfranchised Grief

Doka[57] defines disenfranchised grief as "grief that results when a person experiences a significant loss and that the resultant grief is not openly acknowledged, socially validated or publicly mourned. In short, although the individual is experiencing a grief reaction, there is no social recognition that the person has a right to grieve or a claim on social sympathy or support." Those who are grieving the loss of relationships that may not be publicly acknowledged—for example, with a mistress or with a family conceived outside a legally recognized union, or in some cases with stepfamilies, colleagues, or friends—are not accorded the deference and support usually afforded the bereaved. Furthermore, unsanctioned relationships may result in the exclusion of individuals not legitimated by blood or legal union. Individuals in relationships of long-standing who care for their partners throughout their last illness may find themselves barred both from the funeral and from the home that was shared. For some time, infection with HIV was hidden from the community, thereby depriving both the infected and their caregivers support. The AIDS quilt has done much to provide a public mourning ritual but has not alleviated the disenfranchised status of gay or lesbian partners. This response to stigmatization constrains the public display of mourning by the griever. In this situation, the griever is not recognized. The griever with intellectual disabilities may also not be recognized. McEvoy and colleagues[58] examined the degree to which the person with intellectual disabilities comprehends the finality, universality, and inevitability of death. They conclude that there is only a partial understanding of death by their sample of individuals with intellectual disabilities. It is worth noting that some of the responses given could easily have been uttered by those without such disabilities. Clute[59] found that bereaved people with intellectual disabilities often grieve alone and are disconnected, with little help for their grief. As with any bereaved person, the most helpful approach is an individualized one.

There are other instances in which a loss has not been legitimized. Loss resulting from miscarriage or abortion has only recently been recognized. In Japan, a "cemetery" is devoted to letters written by families each year telling miscarried or aborted children about the important events that occurred in the family that year and also expressing continued grief at their loss. Grieving in secret is a burden that makes the process more difficult to complete. Disenfranchised grief may also be a harbinger of unresolved grief.

Unresolved Grief

Unresolved grief is a failure to accomplish the necessary grief work. According to Rando, a variety of factors may give rise to unresolved grief, including guilt, loss of an extension of the self, reawakening of an old loss, multiple loss, inadequate ego development, and idiosyncratic resistance to mourning.[60] In addition to these psychological factors, such social factors as social negation of a loss, socially unspeakable loss, social isolation and/or geographic distance from social support, assumption of the role of the strong one, and uncertainty over the loss (e.g., a disappearance at sea) may be implicated in unresolved grief. By helping significant others express their feelings and complete their business before the death of a loved one, unresolved grief and the accompanying manifestations can be prevented to some extent.

Eakes and colleagues[61] questioned whether "closure" is a necessary outcome. They explored the concept of "chronic sorrow" in bereaved individuals who experienced episodic bouts of sadness related to specific incidents or significant dates. These authors suggested the fruitfulness of maintaining an open-ended model of grief. With this in mind, grief is always unresolved to some degree; this is not considered pathological but rather an acknowledgment of a death. This model is now known as the theory of chronic sorrow.[62]

Expressions of Grief

In some of the earlier sections of this chapter, various manifestations of grief were mentioned. It is important to note that what is considered appropriate in one group may be considered deviant or even pathological in another. It bears repeating that the manifestations of grief and bereavement are influenced by culture.[63]

The perception of expressions of grief is also framed by professionals. For example, intense grieving beyond 2 weeks is considered in need of psychiatric intervention in the DSM-5.[35] In previous versions of the manual, grief was considered an exclusion for a diagnosis of major depressive disorder if bereavement occurred within a year, and subsequently 2 months, and now, in the current edition of the manual, 2 weeks. This has been a source of considerable debate, with professionals in the field of death and dying decrying such as approach as ill-advised and inappropriate. To quote from a letter from these experts: "Death is a life-altering event, but grief is not a pathological condition."[64] That is not to say that there are no physical, cognitive, and emotional responses to the death of a loved one. Balk and colleagues state, "We are concerned that for reasons of economic profit and clinical efficiency, people will often be prematurely diagnosed with depression and put on medication, rather than offered person-to-person counseling. Clinicians report anecdotally that this practice already occurs."[65(p. 208)] Wakefield warns against pathologizing grief when he states that the "grief process is less a step-wise preset series of events that lead to full resolution of pain, as classically portrayed, and more an individually constructed compromise between a degree of pain that never fully resolves and the need to compartmentalize that pain to move on with one's life."[66(p. 509)] Wakefield concurs with Bowlby that "normal grief can be a very lengthy process."[66]

In Table 31.1, physical, cognitive, emotional, and behavioral symptoms of grief are presented. Table 31.1 is not exhaustive of all of the potential symptoms, but rather is illustrative of the expressions and manifestations of grief. What distinguishes so-called normal grief is that it is usually self-limited. Manifestations

Table 31.1 Manifestations of grief

Physical	Cognitive	Emotional	Behavioral
Headaches	Sense of depersonalization	Anger	Impaired work performance
Dizziness	Inability to concentrate	Guilt	Crying
Exhaustion	Sense of disbelief and confusion	Anxiety	Withdrawal
Muscular aches	Idealization of the deceased	Sense of helplessness	Avoiding reminders of the deceased
Sexual impotency	Search for meaning of life and death	Sadness	Seeking or carrying reminders of the deceased
Loss of appetite	Dreams of the deceased	Shock	
Insomnia	Preoccupation with image of deceased	Yearning	Overreactivity
Feelings of tightness or hollowness	Fleeting visual, tactile, olfactory, auditory hallucinatory experiences	Numbness	Changed relationships
Breathlessness		Self-blame	
Tremors		Relief	
Shakes			
Oversensitivity to noise			

Source: Adapted from Reference 18.

of grief at 1, 3, and 15 months after a death are not the same in intensity. The widows in the study by Kowalski and Bondmass,[67] while experiencing a decline in symptomatology, also continued experiencing symptoms for up to 5 years—the limit of the bereavement experience of the research participants. Studies such as this may change our perceptions about grief.

A Question of Support

How important is the contribution of formal support in addition to the support of the social network of family and friends? The following sections will explore answers to this question.

Formal Support

Who needs support? The data provided by Aoun and colleagues[68] suggest that 68% of men and 54% of women are at low risk and need for bereavement support; 30% of men and 38% of women are at moderate risk, and 2% of men and 8% of women are at high risk and need for support.

Many of the mourning practices noted previously provide support by the community to the bereaved (Table 31.2). Formal support in the Jewish tradition is exemplified by the practice of attending a minion for the deceased person. The minion expresses support for the living. It is formal in that it is prescribed behavior on the part of observant Jews and incorporates a prayer service.

Other examples of formal support include support groups such as the widow-to-widow program and the Compassionate Friends for families of deceased children. The assumption underlying the widow-to-widow program is that grief and mourning are not in and of themselves pathological and that laypersons can be helpful to one another. The widow-to-widow program provides a formal mechanism for sharing one's emotions and experience with individuals who have had a similar experience. The Widowed Persons Service offers support for men and women via self-help support groups and a variety of educational and social activities. The Compassionate Friends, also a self-help organization, seeks to help parents and siblings after the death of a child. Other support groups may or may not have the input of a professional to run the group. Being in such a group, one doesn't have to explain oneself. The other participants have "gone through something so close, it's quite scary."[69(p. 9)]

Table 31.2 Bereavement practices

Lay	Professional
1. Friendly visiting	1. Clergy visiting
2. Provision of meals	2. Clergy counseling
3. Informal support by previously bereaved	3. Nurse, MD, psychologist, social worker, psychiatrist, counseling
4. Lay support groups	4. Professionally-led support groups
5. Participation in cultural and religious rituals	5. Organization of memorial service by hospice and palliative care organizations
6. A friendly listener	6. A thoughtful listener
7. Involvement in a cause-related group	7. Referral to individuals with similar cause-related concerns
8. Exercise	8. Referral to a health club
9. Joining a new group	9. Referral to a bereavement program

Aoun et al.[70] underscore the importance of using social networks. For those bereaved by suicide, Shields and colleagues suggest psychoeducation.[71] The importance of support and acceptance in such cases cannot be underemphasized given the higher risks of developing a mental disorder.[9,72] The question is whether support is readily available to what some may consider a devalued death, such as one by suicide or substance misuse—in essence a voluntary death, a stigmatized death.[73] Bottomley, Burke, and Niemeyer found that social support was associated with "reduced emotional struggles" by the grievers in the sample.[74]

Formal programs for children's bereavement support include peer support programs and art therapy programs. Institutions with bereavement programs, whether for children or adults, often send cards at the time of a patient's death, on the birthday of the deceased, and at 3, 6, 12, and 24 months after the death. Pamphlets with information about grief, a bibliography of appropriate readings, and contact numbers of support groups are also helpful. Family bereavement programs have been found to lead to improved parenting, coping, and caregiver mental health. The provision of bereavement follow-up to parents who have experienced the loss of a child or a pregnancy loss is helpful to the parents and also has implications for the support of the nurses and others who deliver this service.[75]

Attention to staff bereavement support has been given by institutional trauma programs, in emergency departments, and in critical care departments.[76] Brosche[77] provides a description of a grief team within a healthcare system. Keene, Hutton, Hall, and Rushton[78] outline a format for bereavement debriefing. This attention to the grief of healthcare providers empowers those involved to express their grief rather than to suppress it. All of these programs, whether for healthcare providers or family and significant others, maintain contact with the bereaved so as to provide support and make referrals to pastoral care personnel and other professionals as needed.

A variety of approaches have been used in working with the bereaved. Indeed, the combination of "religious psychotherapy" and a cognitive-behavioral approach was observed to be helpful to highly religious bereaved persons.[79] Religious psychotherapy for a group of Malays who adhered to the religion of Islam consisted of discussion and reading of verses of the Koran and Hadith, the encouragement of prayers, and a total of 12–16 psychotherapy sessions.[79] Targeting the follow-up approach to the characteristics of the population eschews the notion that "one size fits all."

Another approach to the provision of support was explored by means of a questionnaire to those bereaved by the death of a relative. They used the information obtained to develop various resources including booklets, posters, and educational sessions to build community capacity to support bereaved individuals.[80]

The evaluation of palliative care by the relative of the deceased family member varied by the setting in which the death occurred, with the home rated most highly followed by hospices. Hospitals and residential settings for the elderly received lower ratings.[81] Hospitals are examining the role they can play in end-of-life (EOL) and bereavement care. Participation in research by bereaved family members of intensive care unit (ICU) patients was determined not only to be feasible but therapeutic.[82] The queries as to their experience and feelings made these family members feel cared for and addressed their need to express their feelings about the ICU experience. In further research, Kentish-Barnes and colleagues examined the impact of a condolence letter for bereaved family members who died in the ICU.[83] While such a letter was perceived as supportive by some, for others it reaffirmed the reality of the death of their family member. When bereavement care is offered, it is usually provided by nurses.[84] In Australia and New Zealand, nurses provide bereavement care in the ICU after a death there, including the removal of clinical paraphernalia, cleaning the patient and straightening the bed, and the use of special attractive bedding and flowers if available, as preparation for family members visiting their dead relative.[85] Bereavement care as part of acute care may compete with other clinical demands, making such support challenging.[86] However, where such support is present, it can be helpful; and obviously, where and when it is not, informal support becomes crucial.

A recent study investigated the impact of advance care planning for the families of dialysis patients.[87] Surrogate family decision-makers and terminally ill patients participated in an intervention that included information/education about the patient's illness as well as end-of-life care and the opportunity to express their feelings about the situation and the choices that needed to be made. The intervention helped participants understand the illness, strengthened relationships between patients and family surrogates, and helped surrogates feel prepared for and comfortable with the decision-making attendant to EOL care. Not everyone is privy to such beneficial interventions.

Support groups may be open-ended (i.e., without a set number of sessions), or they may be closed and limited to a particular set of individuals. Support groups with a set number of sessions have a beginning and end and are therefore more likely to be closed to new members until a new set of sessions begins. Open-ended groups have members who stay for varying lengths of time and may or may not have a topic for each session. Lev and McCorkle[88] cited the finding that short-term programs of 2–7 sessions, or meeting as needed, were the most effective.

Other formal support entails working with a therapist or other healthcare provider (bereavement counseling). The 6- to 8-week programs run by the Lifeline Community Care Group Brisbane for those who were bereaved as a result of a suicide helped to normalize the suicide bereavement experience.[69] Cloyes and colleagues[89] caution that the style of the interaction, whether directive or facilitative, has an impact on the opportunity for expression by the family caregiver. Arnold[89] suggests that the nurse should follow a process to assess the meaning of loss, the nature of the relationship, expressions and manifestations of grief, previous experience with grief, support systems, ability to maintain attachments, and progression of grief. Furthermore, Arnold underscored the importance of viewing grief as a healing process (Box 31.1). She gave the following example of a patient situation and two different approaches to diagnosis[90]:

> A newly widowed woman feels awkward about maintaining social relationships with a group of married couples with whom she had participated with her husband.

◆ Grief as a pathological diagnosis: social isolation.[90]

Bereavement support was demonstrated to have an impact on the grief of gay individuals and was found to be important for bereaved women living with HIV who were at an increased risk for psychiatric conditions and suicide.[91] The risk reduction effects of community bereavement support for HIV-positive individuals was demonstrated by a community support program in Ontario, Canada.[92] These outcomes have implications for the approaches nurses use with other bereaved clients.

Box 31.1 Assessment of Grief

The bereaved often are weary from caring for the deceased. During this period, they may not have looked after themselves. An assessment should include:

1. A general health checkup and assessment of somatic symptoms
2. A dental visit
3. An eye checkup as appropriate
4. Nutritional evaluation
5. Sleep assessment
6. Examination of ability to maintain work and family roles
7. Determination of whether there are major changes in presentation of self
8. Assessment of changes resulting from the death and the difficulties with these changes
9. Assessment of social networks

The healthcare worker needs to bear in mind that there is no magic formula for grieving. The key question is whether the bereaved is able to function effectively. Cues to the need for assistance include:

1. Clinical depression
2. Prolonged deep grief
3. Extreme grief reaction
4. Self-destructive behavior
5. Increased use of alcohol and/or drugs
6. Preoccupation with the deceased to the exclusion of others
7. Perceived lack of social support

In addition to conventional talking therapy, such techniques as letter writing, empty chair, guided imagery, and journal writing can be used (Table 31.3). In letter writing, the empty chair technique, and guided imagery, the bereaved are encouraged to express feelings about the past or about what life is like without the deceased. These techniques can be helpful as the "wish I had said" becomes said. A journal is also a vehicle for recording ongoing feelings of the lived experience of bereavement. A story-telling intervention also shows promise and will be investigated further.[93]

It must be emphasized that grief is not pathology. It is a normal process that is expressed in individual ways. The techniques in Table 31.3 may prove helpful to the individual who is experiencing guilt about things not said or done. This list is not exhaustive, merely illustrative.

Another part of bereavement counseling is the instillation or reemergence of hope. In her exposition of the concept "hope," Stephenson[94] noted the association made by Frankl[95] between hope and meaning. Stephenson stated, "Frankl equated hope with having found meaning in life, and lack of hope as [having] no meaning in life."[94] Meaning-making appears key to the emergence of hope, and hope has been associated with coping.

Table 31.3 Counseling interventions

1. Letter writing	The bereaved writes a letter to the deceased expressing the thoughts and feelings that may or may not have been expressed.
2. Empty chair	The bereaved sits across from an empty chair on which the deceased is imagined to be sitting. The bereaved is encouraged to express his or her feelings.
3. Empty chair with picture	A picture of the deceased is placed on the chair to facilitate the expressions of feelings by the bereaved.
4. Therapist assumes role of the deceased	In this intervention, the therapist helps the bereaved to explore his or her feelings toward the deceased by participating in a role play.
5. Guided imagery	This intervention demands a higher level of skill than, for example, letter writing. Guided imagery can be used to explore situations that require verbalization by the bereaved to achieve completion. Imagery can also be used to recreate situations of dissension with the goal of achieving greater understanding for the bereaved.
6. Journal writing	This technique provides an ongoing vehicle for exploring past situations and current feelings. It is a helpful intervention to many.
7. Drawing pictures	For the artistically and not so artistically inclined, drawing pictures and explaining their content is another vehicle for discussing feelings and concerns.
8. Analysis of role changes	Helping the bereaved obtain help with the changes secondary to the death, such as with balancing a checkbook or securing reliable help with various home needs; assists with some of the secondary losses with the death of a loved one.
9. Listening	The bereaved has the need to tell his or her story. Respectful listening and concern for the bereaved is a powerful intervention that is much appreciated.
10. Venting anger	The professional can suggest the following: ◆ Banging a pillow on the mattress. If combined with screaming, it is best to do with the windows closed and no one in the home. ◆ Screaming—at home or in a parked car in an isolated spot with the windows closed. ◆ Crying—at home, followed by a warm bath and cup of tea or warm milk.
11. Normality barometer	Assuring the bereaved that the distress experienced is normal is very helpful to the bereaved.

In hospice programs, healthcare providers encourage dying persons and their families to have hope for each day. This compression of one's vision to the here and now may also be useful for the person who is grieving the loss of a loved one. Hope for the future and a personal future may be a process that is predicated on hope for each day and having found meaning for the past.

Sikkema and colleagues[91] compared the effectiveness of individual and group approaches by evaluating individual psychotherapy and psychiatric services-on-demand with a support group format. The strategies employed in dealing with grief included establishing a sense of control and predictability, anger expression and management, resolution of guilt, promotion of self-mastery through empowerment, and development of new relationships. Those assigned to individual therapy may or may not have taken advantage of the option. It is proposed that future research examine three groups: those receiving individual counseling, those receiving group therapy, and those assigned no specific intervention but given information about various options for counseling and support in a pamphlet.

A therapist provides an approach for ongoing discussion of the loss that informal caregivers may be unable to provide. A support group of bereaved individuals, or periodic contact with an institutional bereavement service, may also prove useful. What is helpful depends on the individual and his or her needs and also on the informal support that is available. The receptivity of the individual to support, whether formal or informal, is a critical element in whether support rendered is perceived as helpful by the recipient.[96] The underutilization of support by at-risk family members speaks to the need to improve access to those at-risk.[97]

What is a "good death?" According to bereaved family caregivers, it has the following elements:

- *Social engagement*: maintaining relationships and connection to identity
- *Care provider (professional) characteristics and actions*: proactive and empathetic caring
- *Carer's (family) ability*: confidence in caring and understanding the carer's role in "professional caring"
- *Preparation and awareness*: accepting a terminal condition and death
- *Presentation of the patient at death*: control of the dying body
- After death support for protected grieving[98(pp. 837–839)]

Rediscovering the "I" after bereavement is one challenge for bereaved women caregivers. In addition to emotional and social support, the need for practical support for various tasks was also noted.[99,100] The practical support may more likely be secured through informal support.

Informal Support

Informal support occurs among family members and from close friends, neighbors, and colleagues. Listening to the story of the deceased's last days as well as sharing memories is one aspect of this support. The family also has influence on the experience of grief by its members through the shared meanings of the death of their loved one. Indeed, as Naef and colleagues found in their research, the family needs to find a way to make meaning of the death and weave it into their family narrative.[101]

Informal support that is perceived as supportive and helpful can assist the bereaved to come to terms with life after the death of the beloved. Strategies evaluated as being helpful included presence or "being there" indicating "the willingness to listen, and expressing care and concern, whereas the least positively evaluated strategies included giving advice and minimization of other's feelings."[102](p. 419) Whether the bereaved is isolated or is part of a family or social group is of tremendous import to the physical, psychological, and social welfare of the individual. Community in a psychosocial sense and a continuing role in the group are key factors in adjustment.

In societies where the widow has no role without her husband, she is figuratively if not literally disposed of in one way or another. It is for this reason that the woman who is the first in her group to experience widowhood has a much more difficult social experience than a woman who is in a social group where several women already have become widows. In the former, there is no reference group; in the latter there is.

The presence of family and friends takes on added significance after the initial weeks following the funeral. In those initial weeks, friendly visiting occurs with the provision of a variety of types of foods considered appropriate in the group so that the bereaved do not have to be concerned with such activities. The importance of continued support for household tasks, home maintenance, and other financial and legal issues cannot be stressed enough.[99] After the initial period, friendly visiting is likely to decrease, and bereaved individuals may find themselves alone or the objects of financial predators. Counsel by the healthcare provider or by family and friends not to make life-altering decisions (e.g., moving) at this time unless absolutely necessary continues to be valuable advice. On the other hand, the comment that "time makes it easier" is a half-truth that is not perceived as helpful by the bereaved.[103]

What is helpful to the bereaved is listening to music enjoyed by both the deceased and the bereaved[104] and the bereaved being listened to by an interested person. Having family members with whom to grieve has been shown to be significant for grief processing and may enhance family bonding.[103] Quinton disliked the term "counseling" in that it implies the availability of a person with good counsel to offer.[105] What Quinton considered important was "lots of listening to what the victim wants to off-load."(p. 32) She observed, "The turning point for me was realizing that I had a right to feel sad, and to grieve and to feel miserable for as long as I felt the need."[105](p. 32) By owning the grieving process, Quinton provided herself with the most important support for her recovery from a devastating experience—her mother's murder in a massacre by the Irish Republican Army in 1987. The lesson is applicable, however, to any bereaved person regardless of whether the death was traumatic or anticipated. Quinton's turning point is another clue to answering the question of the next section of this chapter: When is it over?

When Is It Over?

To use the colloquial phrase, it's not over until it's over. What does this mean? As long as life and memory persist, the deceased individual remains part of the consciousness of family and friends. When is the grieving over? Unfortunately, there is no easy answer, and the only reasonable response is "It depends." And grief work is never over, in the sense that there will be moments in years to come when an occasion or an object revives feelings of loss. The difference is that the pain is not the same acute pain as that experienced when the loss initially occurred. How one arrives at the point of accommodation is a process termed "letting go."

Letting Go

The term "letting go" refers to acknowledgment of the loss of future togetherness—physical, psychological, and social. There is no longer a "we," only an "I" or a "we" without the deceased. Family members speak of events such as the first time a flower or bush blooms, major holidays, birthdays, anniversaries, and special shared times. Corless[106] quoted Jacqueline Kennedy, who spoke about "last year" (meaning 1962–1963) as the last time that her husband, John Kennedy, experienced a specific occasion:

> On so many days—his birthday, an anniversary, watching his children running to the sea—I have thought, "but this day last year was his last to see that." He was so full of love and life on all those days. He seems so vulnerable now, when you think that each one was a last time.

Mrs. Kennedy also wrote about the process of accommodation, although she didn't call it that[106]:

> Soon the final day will come around again—as inexorably as it did last year. But expected this time. It will find some of us different people than we were a year ago. Learning to accept what was unthinkable when he was alive changes you.

Finally, she addressed an essential truth of bereavement:

> I don't think there is any consolation. What was lost cannot be replaced.[106]

Letting go encompasses recognizing the uniqueness of the individual. It also entails finding meaning in the relationship and experience. It does not require cutting oneself off from memories of the deceased. It does require accommodating to the loss and to the continuing bonds with the deceased.

Continuing Bonds

Klass and colleagues[37] contributed to the reformulation of thinking on the nature of accommodating to loss. Although theorists postulated that the grief process should be completed in 1 year (or less), with one's emotional energies once again invested in the living, the experience of the bereaved suggested otherwise. Bereaved persons visit the grave for periodic discussions with the deceased. They gaze at a picture and seek advice on various matters. They maintain the presence of the deceased in their lives in a variety of different ways—some shared and some solitary. Such behavior is not pathological.

It is a common expectation that teachers in the educational system will have an influence on their students. The students' progress may or may not have continuing contact with those educators. Given that assumption about education, how could we not expect to feel the continuing influence and memory of those informal teachers in our lives, our deceased family members and friends? Integration of those influences strengthens the individual at any point in his or her life.

A Turkish expression in the presence of death is, "May you live."[107] That indeed is the challenge of bereavement. In this next section, we explore in depth death before its time.

Untimely Death

Death that occurs before the anticipated end of life in old age is perceived as a tragic event with distinct characteristics. The most prominent of such untimely deaths is arguably the death of a child. This section will discuss the research findings on parental bereavement and the role of the nurse in addressing these specific needs.

Parental Grief: Characteristics

The two primary tasks facing grieving parents are (1) expressing their intense pain and raw emotions and (2) honoring their deceased child.

The extent of the longing for the child is impossible to imagine for those who have not experienced it and tortuous for those who do. Although such grieving has the same characteristics of all grief, the extent in both force and duration is far greater than most grieving of other losses. In this sense, parents are often misunderstood and judged as "not coping" by the continuation of grieving well past the first or second anniversaries of the child's death. Phrases such as "moving on" or "closure" are particularly unhelpful and inaccurate, since parents learn to live with their loss, not recover from it.[108,109]

One study of 503 parents (predominantly mothers) of deceased babies or stillborns found 51% suffering depression and 42% scored clinically on the Impact of Event Scale several years after the loss.[110] Older parents often feel disenfranchised since losing an adult son or daughter results in the same intense bereavement as the death of a young child but is rarely acknowledged as such by the community.[111] Bereaved parents globally agree that the pain of loss never leaves them but rather softens over many years, becoming a continual thread in the tapestry of their lives, one they have learned over time about which to keep silent in order to avoid judgment.[112]

Extreme grief results in physical symptoms as well as emotional ones. Parents commonly feel significant fatigue, insomnia, gastrointestinal distress, and anxiety. Loss stimulates a cortisol response and hormone imbalance, as well as immune dysfunction. Exacerbations of chronic illnesses and other stress symptoms are likely to occur in the first months or years following a significant loss.[109,113,114]

In addition to the profound longing for the deceased, other emotional and mental changes are also distressing for those experiencing untimely loss. All grief results in distraction, inability to concentrate, and forgetfulness.[115] Any hurt stimulates anger, but grieving parents commonly also feel guilt, shame, and self-blame.[116,117] Parents commonly regret past behaviors and interactions and often blame themselves for the loss, even irrationally.[112] Elderly parents commonly feel survivor's guilt for still being alive when their children are deceased.[111] Negative thoughts such as self-blame or anger toward others have been shown to predict depression and prolonged grief in parents.[118] Parents need to find a path toward forgiveness, both for themselves and for any others whom they may blame. Such forgiveness is associated with less grief and more posttraumatic growth, but may take many years.[109,119]

Continuing the bond with the deceased child is critically important to parents and strongly associated with effective coping.[120] Bereaved parents counsel one another to visit the grave, collect photos, keep possessions, talk to the child, and continue to honor the child in every way that comforts them.[111,121] Parents also use symbolic or ritual representations to continue the bond.[112] Parents now use Facebook or other social media to create memorials and honor their child.[119] High degrees of such activities and continuing the bond with the child is associated with higher posttraumatic growth in bereaved parents.[122]

For many parents, continuing the bond and honoring their child evolves into a form of giving. Many parents express their grief by helping others in some meaningful way and giving back to the community.[123] Such philanthropy is a way of making sense of the child's death, creating good from their pain.[124] Such giving eases the pain of loss and helps to provide meaning to the loss. Seeing some kind of good come from their loss is associated with lower grief intensity and length as well as lower depression.[125,126] For many parents, making meaning out of this tragedy comes in the form of spiritual or religious beliefs and practices.[121] Spiritual activities, such as reflection and relating to others, are associated with lower symptoms of grief, lower posttraumatic stress, and lower depression in mothers, while religious activities are associated with greater personal growth.[127] Posttraumatic growth is positively correlated with increased activities in helping behaviors, relating to others, spiritual change, and appreciation for life.[110,128] Parents report new perspectives and new priorities following the death of a child, as well as increased compassion, empathy, and sympathy for others.[108,125]

Family Dynamics in Grief

Parental grieving greatly impacts both the spouse and the remaining children, which compounds and augments each person's suffering.[129,130] Often the timing of the waves of grief differ, so one spouse may be in extreme pain while the other finally is able to think about something else and is savoring the small break from the constant sadness.[112] Some men and women may grieve differently.[131] Research suggests that men may be more likely to be work and task-oriented, expressing their pain with busyness, while women may cry, talk, and express their emotions outwardly while being very child-focused.[109,132] Several studies indicate that open communication between partners is key. Avoidance of talking about the loss with the partner is associated with higher levels of grief in both partners.[133] In contrast, high levels of communication about the stress of loss correlate with higher levels of posttraumatic growth.[122] Sharing emotions with each other and maintaining bonds with their child helps both the marriage relationship and each individual's level of grief. Parents who integrate the memory of their child into ongoing life appear to experience less suffering.[134]

Role of the Palliative Care Nurse with Parents

Death is the ultimate loss of control, and families feel a distressing helplessness watching their loved one's condition deteriorate. In order to cope with such extreme loss, family members commonly grab for control of any little detail that they are able to influence. Family demands and unreasonable requests of nurses are expressions of the family's cry for help. Near the end of their child's life, parents may continue to express hope for a positive outcome, even if they know such an event would be miraculous. Such hope is not denial, but rather loyalty. Families may feel they are betraying their loved one to give up on life prior to the very last breath.[114] Family members experience lower grief when they are allowed to participate in rituals and have increased control over

EOL activities.[135] For example, parents, especially, experience less extreme distress and lower depression when they are allowed to have unlimited time with their child's body as well as keeping the body at home for viewing.[136,137]

Nurses play a critical role in validating the family's feelings, showing respect and sensitivity for their needs and their religious traditions.[138,139] Family members expect nurses to show great empathy, listening to their feelings, comforting with touch, and offering practical help.[109] Families identify a caring relationship with the nurses as extremely important, longing for their compassion and support.[140,141]

At the end of life and immediately after death family members need and want guidance from the nursing staff. They need encouragement to take time to say good-bye, bathing, dressing, holding, and taking photos before and after death, if they wish.[142] Families are in a foreign environment in the hospital and too traumatized to even think about their own needs. Nurses' guidance and suggestions help spouses and parents to capture precious memories that will greatly sustain them in the future. Keepsakes, such as hand and foot prints or a lock of hair, should be provided for parents. When nurses help with such concrete direction, parents later report deep gratitude for the assistance.[143]

Family members may also need practical information at the time of death about making arrangements for their loved one.[123] People in deep grief are by definition compromised in their ability to problem-solve. They need information from an informed and sensitive social worker as to funeral, obituary, and other details. Parents of stillborn or very premature babies commonly see their child as equally worthy of all death rituals and all ways of honoring their child. Parents expect equal treatment and respect for their deceased premature fetus as with any child or family member.[141] Parents and spouses often benefit from connections with other parents and spouses who have experienced similar loss and also desire help finding such peer bereavement groups.[123,142] Bereaved mothers and fathers also hope nurses and other healthcare professionals will provide information to their family and friends on how to support bereaved parents.[112,114,140]

Bereaved family members often turn to social media sites for peer support and especially crave contact with other parents in similar situations, such as suicide survivors.[123,141,144] Such online groups allow them to identify with other families in grief, express their feelings in a "safe" environment, and honor their loved one with photos and memories.[145]

Bereaved parents long for contact with their child's nurse well beyond the immediate day of death. They want the nurses who were like family to them in their darkest hours to continue to support them during the funeral and the months following the loss, although these parents wait for the staff to initiate such contact.[140,146] Bereavement services provide important continuing care for families, who also value phone calls from the nurses whom they knew well.[147,148]

Most importantly, nurses give critical support by words of affirmation. Family members long to hear positive words about their deceased loved one, especially when experiencing the acute pain of loss, but also for all of their lives.[114] Specific, sincere, positive feedback to families on any topic, from their physical appearance to behaviors or decisions, provides enormous emotional support to bereaved families, like a tremendous hug.[114] Since self-esteem is challenged by the death of a loved one, mourners who can hold on to their self-worth report lower symptoms of posttraumatic stress and depression.[123] Receiving gestures of compassion and support, especially during the most vulnerable moments of grief, helps to encourage positive transformation and growth long term for bereaved families.[142] Research has demonstrated that positive experiences with nurses can impact grief intensity and the coping ability of bereaved families.[138,147,148]

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CHAPTER 32

Supporting Families and Family Caregivers in Palliative Care

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Key Points

- When a family member is faced with a life-limiting illness, it affects both individual family members and the entire family.
- Family members who provide care—family caregivers—require support from nurses and the healthcare system to sustain them in their caregiving role. The health and well-being of the family caregiver is just as important as those of the patient.
- Family members look to nurses and other health professionals to provide quality care to the patient in palliative care but also expect nurses to meet their needs for information, emotional support, and assistance with care. For the vast majority of families and their members, contributing to the care of their loved one is important. Individualizing care for each family and its members is a key role for nurses who provide family-centered palliative care.

Introduction

When a family member is faced with a life-limiting illness, it affects the entire family. Anticipating the loss of a significant other not only causes disruptions to the family unit as a whole but can challenge individual family members to make sense of the impending loss. Many families show resilience and adaptation in the face of such stress, and these experiences have the potential to create a deeper sense of meaning and connection among family members.[1] At the same time, research suggests a significant percentage of family members—18–35%—experience some form of psychiatric morbidity,[2] and if family members are giving care—family caregiving—the physical and financial consequences can be substantial.[3]

Nurses working with people who are dying are in a primary position to provide support to family members and families as a whole. Family-centered care is an important part of nursing practice, and, in the context of palliative care, the family as the unit of care has been central since the inception of the modern hospice and palliative care movement. The World Health Organization states explicitly that palliative care should not only improve the quality of life (QOL) for patients but also for their families. A family's experience of having an ill member is best understood in the context of their relationships with each other, and this becomes even more so when a family member is ill and is requiring care.[4] Changing patterns of dependency, reciprocity, and the rewards and challenges that arise influence each family in different ways. As such, "palliative care is predominantly a family affair,"[4(p. 278)] experienced uniquely for each family and the individuals in it.

This chapter focuses on the family as the unit of care and also places emphasis on family caregivers in palliative care. Family members who provide care to a loved one make substantial contributions to the health and social care systems, with estimates suggesting that they provide 80% of all care.[5] Many families willingly assume the role of family caregiver for someone at the end of life, often doing so out of a sense of love, compassion, or feelings of obligations to care. Providing such support can result in positive changes in family members and personal growth,[6] but many families and family caregivers are not always fully aware of the cost to their physical, mental, and financial health.[7] Some family caregivers do not perceive themselves to be in need of support from healthcare professionals and the healthcare system, even when giving care and support to an ill member becomes overly burdensome.[8,9]

In recent years, family caregiving has become more of an issue for several reasons. Improvements in treatments to control the disease mean that end-of-life (EOL) caregiving often comes after a long period of chronic illness. Depending on the illness, the decline toward death is sometimes precipitous, allowing little time for the family and the caregiver to adapt and acquire the necessary knowledge to support the person dying and themselves.[10] Many family caregivers are now asked to perform procedures in the home (and sometimes in the hospital)[11] that were once the exclusive domain of nursing care.[12] Fewer children per family and a more mobile society mean that there are usually fewer family members to care for dying relatives.[13] And, since we are living longer with more comorbidity, caregiving is more complex; spouse caregivers are older and often have their own serious illnesses as well.[13]

As a basis for offering optimal support to families in palliative care, this chapter will discuss family-centered palliative care and the experience of family members in supporting their significant others. In addition to presenting research that will inform nursing interventions for families, this chapter will include what is involved in being a family caregiver and some of the challenges that family caregivers face. In keeping with a core focus in palliative care on QOL, important elements in promoting family caregiver QOL and the needs of caregivers will be outlined. Considerations in family caregiver assessment and how to support family caregivers in the home, the hospital, and in intensive care and perioperative settings will also be highlighted, as will the family's role in decision-making and advance care planning, including providing resources that nurses can use to promote family-centered palliative care.

Family-Centered Palliative Care

Recognizing the importance of a family focus necessitates clearly defining what is meant by "family" and "family caregiving." Most often, families in palliative care consist of patients, their spouses, and their children. But, in today's world of divorce, repartnering, remarriage, and cohabitation,[14–16] step-relatives must also enter into the family portrait. In other instances, people unrelated by blood or marriage (also referred to as families of origin and families of choice),[17,18] or families made up of lesbian, gay, bisexual, trans, and queer or questioning (LGBTQ) individuals mean that our traditional definitions of families in palliative care must necessarily be broad and diverse.[15] Census definitions of family have tended to focus on defining family as people living in one household, but we know that not all family members live together, and how family is defined can vary from country to country.[19]

For the purposes of this chapter, family is defined as a group of individuals inextricably linked in ways that are constantly interactive and mutually reinforcing. Family can mean direct blood relatives, relationships through an emotional commitment, or the group or person with whom an individual feels most connected.[17] In its broadest sense, family is defined as whoever the person says his or her family is, including relatives, partners, neighbors, and friends.[17] Family caregivers in this context are defined as individuals who provide unpaid care and/or support to a family member, friend, neighbor, or significant other who has a physical or mental disability, is chronically ill, or is frail, and, in particular, is diagnosed with a disease where the likelihood of death is high.[19]

Palliative care programs are based on the principle that the family is the unit of care. In practice, the family is often viewed as a group of individuals who are sometimes perceived to be helpful or to resist efforts to deliver care. Regardless of the family situation and composition in palliative care, nurses and other health professionals must strive to understand the meaning of the palliative experience to the family as a whole, as well as to its individual members.[20] Some of the best outcomes are achieved when appropriate interventions are directed toward family members both individually and as a group. [20,21] If quality care is to be provided, nurses need to understand how all family members perceive their experience, how the relationships fit together, and that a multitude of factors interact to make families what they are.[21]

In the past 10–15 years, research has gone beyond focusing on the needs of dying patients for comfort and palliation to addressing issues relevant to other family members. Much of this research has focused on the family's perceptions of their needs,[22,23] experiences and challenges faced,[13] adaptation and coping skills required for home care,[24,25] the supportiveness of nursing behaviors [26,27] or physician behaviors,[28] and satisfaction with care.[27] Though research used to focus primarily on families of patients with cancer, palliative care extends the focus to other life-limiting illnesses. Reports for other diagnostic populations, such as Parkinson's disease,[29,30] heart disease,[31] motor neurone disease,[32] lung disease,[28,33] kidney disease,[34,35] and neurodegenerative diseases[26,28] are becoming more available, as is research and clinical care focused on the care needs of people with dementia and their families.[36,37] Regardless of disease or condition, research makes it clear that family members look to nurses and other health professionals to provide quality care to the patient.[34] Family members expect health professionals to meet their needs for information, emotional support, and assistance with care.[27] Recent research suggests that one of the most effective ways to support families may be to help them be successful in their caregiving roles.[27] Providing care might not always be what family's desire,[38] but, for the vast majority of families and their members, contributing to the care of their significant other is important. Individualizing care for each family and its members is a key role for nurses who provide family-centered palliative care.

Understanding the Experiences of Families in Palliative Care

The Transition of Fading Away

When a family member is faced with a life-limiting illness, the impending death presents a challenge to the entire family. Family members must try to find new balance during the illness and after their significant other has died. One of the most comprehensive research programs directed toward understanding the experiences of families in palliative care evolved from nurses' concerns about how to provide family-centered palliative care.[39] As authors of the previous version of this chapter, Steele and Davies[40] noted that nurses in a regional cancer center constantly had to attend to the needs of not only patients but also patients' families, particularly as they moved back and forth between hospital and home. In searching the literature for guidelines about family-centered care, Davies and her colleagues found that many articles were about the needs of patients and family members, about levels of family members' satisfaction with care, and about family members' perceptions of nurses, but nothing really described the families' experiences as they coped with the terminal illness of a beloved family member. Their research program, studying families of patients with advanced cancer, and later, families with AIDS, Alzheimer's disease, cardiac disease, and families of children with progressive, life-threatening illness resulted in a conceptualization—the *transition of fading away*—as a basis for thinking about the experiences of families in palliative care.[39]

The transition of fading away is characterized by seven dimensions: redefining, burdening, struggling with paradox, contending with change, searching for meaning, living day by day, and preparing for death. The dimensions do not occur in linear fashion; rather, they are interrelated and inextricably linked to one another. While a common view is that transitions are initiated by changes, by the start of something new, Bridges[41] suggests that most transitions actually begin with endings. This is true for families in palliative care. As Davies et al. found, the transition of fading away begins with the ending of life as a person knows it. Family members come to realize that the ill family member is no longer living with a life-limiting illness but is now dying from it.

Despite the fact that family members have been told about the seriousness of the prognosis, often since the time of diagnosis, they experience the usual ups and downs associated with the illness trajectory; for many the "gut" realization that a patient's death is inevitable occurs suddenly: "It struck me hard—it hit me like a bolt. Dad is not going to get better!" The awareness is triggered when family members see, with "new eyes," a change in the patient's body or physical capacity, such as the patient's weight loss, extreme weakness, lack of mobility, or diminished mental capacity. Realizing that the patient will not recover, family members begin the transition of fading away. As one patient commented, "My body has shrunk so much—the other day, I tried on my favorite old blue dress and I could see then how much weight I have lost. I feel like a skeleton with skin! I am getting weaker. . . . I just can't eat much now, I don't want to. I can see that I am fading. . . . I am definitely fading away." To help further illustrate the transition of fading away, we use exemplars from our own clinical work and studies with families in palliative care.

Dimensions of the Transition of Fading Away

Redefining

Redefining involves a shift from "what used to be" to "what is now." It demands adjustment in how individuals see themselves and each other. Patients maintain their usual patterns for as long as possible, and then begin to implement feasible alternatives once they realize that their capacities are seriously changing. Shelly, a young woman diagnosed with metastatic colon cancer, redefined what she was capable of as her illness progressed. Once an avid tap dancer, she could no longer participate in dance competitions in her age group. As she became more fatigued, she gave up dancing altogether but was still able to help her dance group behind the scenes with costume changes and make up. As her illness progressed, she became an audience member, cheering on her dance company. One day, Shelly realized that even that required more energy than she had. She was able to maintain connections with her dance community even toward the very end of her life, but those connections changed and were redefined; her family kept her updated about the dance group, posted pictures in her bedroom of her "dance friends" and made arrangements for friends to visit when Shelly felt well enough. Another patient, Fred, owned a landscaping business, and, as his chronic obstructive pulmonary disease progressed and he became increasingly short of breath, he could no longer do the physical work required. Fred lamented that he loved being out in the garden, but as time went on, he took over book-keeping duties while his son took over the family business. Eventually, he could no longer do that as his health deteriorated.

Both Shelly and Fred, like other patients, accepted their limitations with much sadness and a sense of great loss. Their focus narrowed, and they began to pay attention to details of everyday life that they had previously ignored or overlooked. While Shelly wanted to maintain connections to her dance community, over time, that became more difficult and she set her sights on spending more time with family and her nieces and nephews. Both Shelly and Fred talked about feeling "the same on the inside," although they acknowledged the drastic changes in their physical appearance. Some patients, like Shelly, became more spiritual in their orientation to life and nature. Early in her illness, Shelly organized groups of friends to go to the ocean early in the morning for a "healing circle," where meditation, yoga, and prayer were practiced. When patients are able to redefine themselves as Shelly did, they made the best of their situation, differentiating what parts of them were still intact. While Fred could no longer continue working as a landscaper, he could still enjoy going into his own backyard and "puttering around" when he felt well enough. His son, Jeremy, even built a backyard gazebo where Fred took up bird watching; he replaced one joy in life with another as a way to continue to connect with the outdoors.

Patients who are unable to redefine themselves in this way often attempt to maintain their regular patterns despite the obvious changes in their capacity to do so. Sometimes patients end up frustrated, angry, and feeling worthless. These reactions distance them from others, resulting in the patient feeling alone and, at times, abandoned. Lisa, for example, worked in a law office as a paralegal. Even though her health was deteriorating, she was unable to recognize that she could no longer work to full capacity. The demands of her job were high, often with tight timelines and occasions when she had to work overtime. While her workplace and employer were respectful of her need to contribute and maintain her work identity, Lisa had difficulty giving up responsibility. As the work piled up, it became clear that she could no longer complete assigned duties. Her co-workers began helping Lisa with her work, often working overtime themselves. At first, they were happy to help, but, as the months went by and Lisa's health further deteriorated, some co-workers started to feel resentful. Lisa became increasingly frustrated with her inability to complete work on time and increasingly angry with her boss who she felt was too demanding. Eventually, Lisa was encouraged to take time off work, with pay, to enable her to look after herself. Her husband remarked that not being able to work was devastating to Lisa who had previously enjoyed her job and who still felt that she was able to work to full capacity. While Lisa continued to have a relationship with her co-workers once she left work, her husband remarked that it was awkward and strained at times. According to Lisa's husband Dan, her co-workers began visiting less and less, leaving Lisa feeling abandoned and misunderstood.

For the most part, we have found that spouses take the patient's physical changes in stride. They attribute the changes to the disease, not to the patient personally and, as a result, are able to empathize with the patient. Patients' redefining tends to focus on themselves, the changes in their physical status and intrapersonal aspects; spouses' redefining centers on their relationship with the patient. Spouses did their best to "continue on as normal," primarily for the sake of the patient. In doing so, they consider alternatives and reorganize their priorities.

Sometimes family members experience the "reciprocity of suffering" that results from the physical and emotional distress that is rooted in their anguish of dealing with the impending death of a loved one and in their attempt to fill new roles as family caregivers. It appears that the degree to which family members experience reciprocal suffering relates to how patients redefine themselves. When patients are able to redefine themselves, spouses have an easier time. Such patients accepted spouses' offers of support; patients and spouses were able to talk about the changes that were occurring. Spouses felt satisfied in the care that they provided. But when patients were less able to redefine, then spouses' offers of support were rejected or unappreciated. For example, Louis was the main trumpet player in a military band. He loved to perform, and when he could no longer keep up with band members, his wife Donna encouraged him to quit, telling Louis that it was unfair to his band members. Louis got angry with Donna, telling her that "you don't know anything, I'm fine." Louis continued to play with the band, having Donna drive him to twice-weekly performances. One night at a performance, Louis collapsed and was taken to the hospital. Donna was frustrated that her concerns had not been heard by Louis, and Louis in turn was upset that Donna did not understand his need to continue performing. Their relationship became strained as Louis struggled to redefine life after his cancer diagnosis, and Donna struggled to know how to best help Louis.

In such situations, spouses often avoid talking about or doing anything that will remind the patient of the changes he or she is experiencing but not acknowledging. This often causes strain in relationships. Rather than feeling satisfied with their care, spouses become frustrated and angry, although often they remain silent and simply "endure" the situation. The ill person contributes significantly to the caregiver's ability to cope. In their systematic review of factors that influence family caregiving of persons with advanced cancer, Li and Loke[42] found that the spousal relationship contributed significantly to the capacity of the spouse to adjust their caregiving role and expectations in order to provide care despite their experience of overwhelming emotional and physical strain. Caregivers drew strength from the dying person when the ill person accepted the impending death, had an understanding of the caregivers' needs, and had attitudes, values, and beliefs that sustained their caregiving.[43]

Adult children also redefine the ill family member; they redefine their ill parent from someone who was strong and competent to someone who is increasingly frail. When Jeremy took over his father's landscaping business, he expressed disbelief at watching his father's strong body wither away. He had always viewed his father as a "strong man," and it was difficult to see him in a weakened state. Jeremy felt vulnerable in ways he had not previously experienced. As Davies and colleagues report,[39] children perceive that the changes in their ill parent are the result of disease and not intentional. Younger children are particularly sensitive to keeping the situation private, claiming they want to protect the dignity of the patient, but they seemed to want to protect their own sense of propriety. For example, one young woman in her early twenties was "devastated" when her father's urinary bag dragged behind him as he left the living room where she and her friends were visiting. It was difficult for some young adults to accept such manifestations of their parent's illness. Adolescents in particular had a difficult time redefining the situation. They preferred to continue on as if nothing was wrong and to shield themselves against any information that would force them to see the situation realistically. This is consistent with more recent research with adolescents who have a dying family member.[44]

When a patient is able to redefine, children are also better able to accept that dying is a natural part of life. Often, children (and others) recommit to their own health when they have a family member who is dying, and the experience causes them to reflect on their own life and the changes that they want to make. Fred's son David, for example, was estranged from his own children as a result of a long history of substance use. Though he had been alcohol-free for 5 years, he had been afraid to reach out to his now teenage children. Fred and his wife had not spent much time with their grandchildren. When David realized that his father was dying, it prompted him to be in touch with his ex-wife, which resulted in a meeting with his children. Fred's illness, while challenging for the family, prompted David to reconnect with his children and allowed Fred the opportunity to spend time with his grandchildren before he died. In contrast, when a dying person is unable to redefine, it can also affect his or her adult children. Dealing with the patient's angry emotions sometimes makes the relationship difficult. Valerie and her mother had experienced conflict in their relationship when Valerie was growing up. When her mom was diagnosed with metastatic cancer and her health began to deteriorate, Valerie began spending more time with her mother than she had in the past, but her mother was not overly receptive. After her mother had died, Valerie expressed regrets and wished that her mother had been able to accept her offers of help. Valerie said that she had spent many hours in bereavement counseling trying to reconcile her feelings about the relationship with her mother, suggesting that her mother's inability to redefine their relationship had affected her personal life in profound ways. The work of Sherman[43] underscores the importance of relationships among and between family members in facilitating their coping with the situation of terminal illness.

Burdening

One of the most common feelings that people who are dying express is a desire to not be a burden to their family.[45] If patients see themselves as purposeless, dependent, and immobile, they have a greater sense of burdening their loved ones. The more realistically that patients redefine themselves as their capacities diminish, the more accurate they tend to be in their perceptions of burdening.[39] They acknowledge other family members' efforts, appreciate those efforts, and encourage family members to rest and take time to care for themselves. According to Steele and Davies,[40] patients who are less able to redefine themselves do not tend to see that they are a burden on other family members in any way. Frances, a retired nurse, retold the story of her husband Bernie and how he did not seem to realize that she needed a break. Frances explained that when Bernie became ill and was no longer able to attend their weekly bridge group, he insisted that she also stay home to be with him. Frances arranged to have home help for Bernie so that she could continue her weekly outing as she found it a great source of support. When Bernie refused the help, Frances felt she had no choice but to give up her weekly game. She commented that Bernie "just didn't seem to have a clue that I needed to get out. . . . It wasn't about him, it was just that I needed the break."

Most spouses acknowledge that providing care and support to a loved one is hard work, and it can be overwhelming. While some spouses do feel overburdened, most often spouses feel a deep desire to provide care to their loved one out of a sense of love and obligation.[9] Spouses often do not focus on their own difficulties and, in fact, often put their own needs aside. Stories of loneliness and helplessness often surface during the experience, but caring for a loved one can also bring couples closer together as they revisit their relationship and deepen their love and respect for one another. Spouses of patients who are able to redefine often feel proud of their caregiving efforts and appreciated for their contributions to their spouse's life and dying process. Spouses of patients who are not able to redefine can feel unappreciated, exhausted, and some have even confessed to "waiting for the patient to die."

Steele and Davies[40] suggest that children, too, experience burdening, but the source stems from the additional responsibilities of helping to care for a dying parent, superimposed on their work responsibilities, career development, and their own families. As a result, adult children of all ages feel a mixture of satisfaction and exhaustion. Debbie's mother was diagnosed with metastatic lung cancer just as she was graduating from university and starting a new job in another city. While Debbie was reluctant to move, her father encouraged her to do so, but, over time, Debbie began to feel the strain of living at a distance. As her mother's disease progressed, Debbie, an only child, would fly home on weekends to help her father but often felt pulled between her work responsibilities and her responsibilities to her family. Both of Debbie's parents were understanding and recognized that Debbie was doing all she could to support them; they appreciated her efforts and were thankful when she was home. Adult children are influenced by the ill parent's redefining—if the ill parent acknowledges their efforts, they are more likely to feel satisfaction. Children's sense of burdening is also influenced by the state of health of the well parent. If that parent is also ill or debilitated, the burden on children is compounded. Children who are able to prioritize their responsibilities while also attending to their own needs do tend to feel less burdened, according to Steele and Davies.[40] As such, nurses can play an important role in coaching adult children toward self-care and balance so that they do not feel burdened by the multiple responsibilities that they can incur when a parent is dying.

Struggling with Paradox

Struggling with paradox stems from the fact that the patient is both living and dying. For patients, the struggle focuses on wanting to believe they will survive and knowing that they will not. Steele and Davies[40] write that on "good days," patients felt optimistic about the outcome; on other days, they succumbed to the inevitability of their approaching demise. Often, patients did not want to "give up" but at the same time were "tired of fighting." They wanted to "continue on" for the sake of their families but also wanted "it to end soon" so their families could "get on with their lives." Patients coped by hoping for miracles, fighting for the sake of their families, and focusing on the good days. Rose, a young woman diagnosed with terminal cancer, rarely talked about dying. Although she had been a palliative care volunteer, had journeyed with many dying people, and was told what the eventual outcome of her diagnosis would be, she focused exclusively on her cancer treatment, on living, and praying for a cure. As her functional status changed, her mobility declined, and she developed pain, it was difficult for Rose to ignore that the disease was progressing. Some days she talked about being healed and on others she doubted that this would happen. It wasn't until 2 days before she died that Rose agreed to register with the palliative care program.

Spouses also struggle with paradox: they want to care for and spend time with the patient, and they also wanted a "normal" life. Frances desperately wanted to continue with her bridge playing for the social outing but also because the social support that the group provided helped her cope with caring for Bernie. Because Bernie feared being left alone, but would refuse help, Frances felt that she had to put her life on hold and soon became exhausted herself. Eventually, Frances decided to invite the bridge group to her home. Even though this created more work for her as she prepared for their arrival, and it was not the complete break that she desired, it did provide her with a welcome distraction and created some normalcy in her life. Steele and Davies[40] report that spouses who manage to find ways of tending to their own needs usually are less exhausted and report fewer health problems than spouses who neglect their own needs.

Children struggle with hanging on and letting go to a greater extent than their parents. They want to spend time with their ill parent and also to "get on with their own lives." Feeling the pressure of dual loyalties (to their parents and to their own young families), the demands of both compound the struggle that children face.

Contending with Change

Those facing terminal illness in a family member experience changes in every realm of daily life—relationships, roles, socialization, and work patterns. The focus of the changes differs among family members. Patients face changes in their relationships with everyone they know.[40] They realize that the greatest change of their life is under way and that life as they knew it will soon be gone. Patients tend to break down tasks into manageable pieces, and, increasingly, they focus inward. The greatest change that spouses faced was in their relationship with the patient. They cope by attempting to keep everything as normal as possible. Children contend with changes that are more all-encompassing; they cannot withdraw as their ill parent did, nor can they prioritize their lives to the degree that their well parent could.[40] They easily become exhausted. As Debbie explained, it was hard to fly home every weekend to help her mother and father. She had just started a new job in a new city, and she wanted to begin building her professional career but she felt "the pull" to be at home. She felt guilty for not being there to help her father with the everyday demands but also stressed at learning her new job and wanting to impress her employer. She contemplated moving home and quitting her job several times, but, in the end, continued to travel back and forth for several months, up until her mother died and she helped her father after her mother's death.

Searching for Meaning

Searching for meaning has to do with seeking answers to help in understanding the situation. Patients tend to journey inward, to reflect on spiritual aspects and deepen their most important connections. Spouses and others close to the dying person often look toward their own personal growth and reconciling issues from the past. Gail and Nancy had been close childhood friends. They spent most of their summers together up until they each got married and moved to different parts of the country. Over time, their relationship became distant but when Gail was diagnosed with bladder cancer, Nancy was the first person she called. Nancy visited Gail and her husband several times over the 2 years before she died. They reminisced about their childhood and young adult days and tried to understand why their friendship had diminished. They sought experiences that reminded them of their earlier times together—going to the beach, fishing, and staying at lakeside cottages. After Gail died, Nancy remarked that spending time with Gail had caused her to reflect and reevaluate her own life. The experience helped her "put things in perspective," and she described becoming less concerned about bolstering her career and more concerned about spending time with family and friends. Children also tend to reflect on and reevaluate aspects of their lives when a parent dies.[40] One son said that his father had worked hard his whole life trying to provide for his children as they were growing up. He often worked late, traveled for work, and missed family celebrations. While he was appreciative of his father's efforts, he vowed to make changes in his own life so that he could spend more time with his children.

Living Day to Day

Living day to day is characterized by a focus on the present, on the "here and now" and trying to make the most of a challenging situation. When patients are able to find meaning in their experiences, they are more able to take one day at a time and often experience less turmoil.[39] Catherine approached her cancer diagnosis pragmatically. She had always been organized, a strong planner, and, when diagnosed with cancer, decided to not dwell too much in "what could have been" but rather focused on "the here and now."

Once she could no longer work, she turned her attention to learning new skills that she could handle and that would keep her busy. She began knitting hats and blankets for her family, and, when she tired, she would put that aside and rest. She was not discouraged, but rather decided on adopting an attitude of living each day to the fullest that she could. Not all patients are able to live day to day. For patients who are unable to find meaning in their situations, they tend to focus on persevering through difficult times and "getting through it."[39]

Spouses who are able to find meaning in the situation were better able to live day to day. They cherished the time that they had with their partner and made the best of things. Fred's wife Betty even suggested that Fred's diagnosis meant that they could spend time in their own garden together after years of Fred landscaping the yards of others. Although they could no longer make their yearly trip to Arizona, Betty said she "didn't mind" as she wanted to make the best of the time that she and Fred had left. Other spouses simply endure the situation without paying much attention to philosophizing about the experience. Steele and Davies[40] comment that children often have difficulty concentrating on living day to day because they are unable to defer their obligations and therefore worry about what else needs to be done. Other children cope differently and are able to "live for the day."

Preparing for Death

In preparing for death, patients, spouses, and children come to terms with the practical aspects of dying. Patients often have their family's needs uppermost in their minds and work hard to teach or guide family members with regard to various tasks and activities that the patient will no longer be around to do. Bea spent many months teaching her husband Harold how to cook and do laundry as he had not been responsible for those tasks in their married life together. Even though it was hard for both of them, Bea was determined that Harold be prepared. Many patients are also committed to leaving legacies for their loved ones, not only as a means of being remembered but also as a way of comforting loved ones in their grief. Gail learning to knit blankets and hats for those she loved enabled her to leave something special behind. She also created multiple memory books for her friends and family.

Spouses tend to concentrate on meeting the patient's wishes. They attend to practical details and anticipate their future in practical ways. Children offer considerable help to their parents with legal and financial matters. They also prepare their own children for what is to come. A central aspect of preparing is reassuring the dying parent that they would take care of the surviving parent.[39] Children also prepare for the death by envisioning their future without their parent.

In summary, the transition of fading away and its related dimensions provide a comprehensive picture of the families' experience in palliative care, how life-limiting illness can affect the family as a whole and its individual members. This conceptualization provides nurses with guidance for interventions with families. Table 32.1 summarizes key strategies that nurses caring for families can use in their everyday practice to promote family-centered palliative care.

Family Caregiving in Palliative Care

The primary goal of palliative care is to improve the QOL and quality of death of dying people and their families through provision of excellent care. Families share most intimately the experience of living with and dying from a life-limiting illness. They are strongly affected, both positively and negatively. Many also wish to provide care, and, in these cases, nurses and other healthcare professionals play a key role in supporting them so that they do not endanger their own health.

Family caregiving in palliative care involves many things, but, at its core, family caregivers provide most of the physical and emotional care for the individual who is dying.[46,47] Family caregivers manage medications, symptoms, and other aspects of patient care,[48] and, as the person who is dying functionally declines and is less able to get out and socialize with others, family caregivers provide social support.[47,49] Providing the person who is dying with practical support for activities of daily living, such as bathing and eating, as well as other household tasks is a common role for family caregivers, including taking on new roles that were previously those of the person who is dying. Family caregivers act as the spokesperson, advocate, and proxy decision-maker for their significant other, and they assume primary responsibility for coordinating the care of the patient.[46,48] There are many challenges for family caregivers. For example:

- The physical demands of providing care can be extremely difficult for family caregivers.[50] Many family caregivers are older and have health concerns of their own, which can make caregiving particularly challenging.[13]
- Developing assessment and caregiving skills may be challenging for family caregivers. They often report that they do not feel prepared for their caregiving role, especially in regards to medication management.[51] Caregiving responsibilities and lack of feeling prepared result in a considerable amount of anxiety and fatigue in family caregivers.[52]
- Family caregivers who look for information to help them prepare for caregiving often feel overwhelmed by the complexity and amount of information needed to fulfill their caregiving role, adding to their stress.[53]
- Caregiving responsibilities, carrying out multiple roles, and often being unable to leave the patient alone result in significant disruptions in family caregivers' regular routines and restrictions on their time and ability to participate in social and health-related activities that they value.[49] Younger caregivers, women, and those who are a child of the person who is dying often find disruptions to their own schedules especially difficult,[54] likely due to the stress of competing demands from work and family life.[46,53]
- Family caregivers may also experience financial stressors associated with caring for a dying person at home.[55] Many family caregivers quit their job, lose work hours, or use special leave or holiday time in order to fulfill caregiving responsibilities.[56] Loss of income and out-of-pocket costs incurred for items such as prescription and over-the-counter medications, home care, and equipment and home modifications result in many family caregivers having some type of financial difficulty due to home-based caregiving.[56,57]

These challenges often leave family caregivers feeling burdened by the demands of care. The literature provides a comprehensive description of the multidimensional nature of the burden experienced by family caregivers. Caregiver burden, commonly experienced by spouses, has been described in terms of physical burden,

Table 32.1 Dimensions of fading away: nursing interventions for family members

Dimension	Nursing interventions
Redefining	Ensure effective symptom management, because this allows patients and family members to focus outside the illness. Appreciate that relinquishing old and comfortable views of themselves occurs over time and does not necessarily occur simultaneously with physical changes in the patient. Tailor interventions according to the various abilities of family members to assimilate the changes.
Contending with change	Reassure family members that a range of responses and coping strategies is to be expected within and among family members. Create an environment in which family members can explore and manage their own concerns and feelings. Encourage dialogue about family members' beliefs, feelings, hopes, fears, and dilemmas so they can determine their own course of action. Provide opportunities for patients to talk about the illness, the enforced changes in their lives, and the ways in which they have adapted; for spouses to talk about how changes in the patient affect their marital relationship; and for children to talk about their own feelings of vulnerability and the degree to which they want to be open or private about the situation. Recognize that families communicate in well-entrenched patterns and their ability to communicate openly and honestly differs. Normalize the experience of family members and explain that such feelings do not negate the positive feelings of concern and affection. Reinforce normal patterns of living for as long as possible and as appropriate. When patterns are no longer viable, consider adjustments or alternatives. Provide information so families can explore the available resources, their options, and the pros and cons of the various options. Provide information in writing as well as verbally. Focus on the patient's attributes that remain intact, and acknowledge that roles and responsibilities may be expressed differently. Consider adjustments or alternatives when former patterns are no longer feasible. Explain the wide-ranging nature of the changes that occur within the patient's immediate and extended family.
Searching for meaning	Help spouses consider how they might reorganize priorities and consider resources to help them do this. Appreciate that the search for meaning involves examination of the self, of relationships with other family members, and of spiritual aspects. Help children appreciate their parent from another perspective, such as in recalling favorite stories or identifying legacies left . Realize that talking about the current situation and their recollections of past illness and losses is part of making sense of the situation.
Burdening	Provide opportunities for patients to talk about fears and anxieties about dying and death, and to consider with whom to share their concerns. Encourage life reviews and reminiscing. Listen to the life stories that family members tell. Help patients stay involved for as long as possible as a way of sustaining self-esteem and a sense of control. Suggest approaches for self-examination such as journal writing, and approaches for facilitating interactions between family members such as writing letters. Assist family members to take on tasks appropriate to their comfort level and skill and share tasks among themselves.
Living day to day	Support family members' reassurances to patient that he or she is not a burden. Explain that when patients reaffirm family members for their efforts, this contributes to their feeling appreciated and lessens the potential for feeling burdened. Listen carefully for the subtle shifts in orientation to living with a dying relative and gauge family members' readiness for a new orientation. Ensure effective control of symptoms so that the patient can make the most of the time available. Assess the need for aids. Explain the importance of breaks for family members. Encourage others to take over for patients on a regular basis so family members can take a break. Without minimizing their losses and concerns, affirm their ability to appreciate and make the most of the time left. Acknowledge the reorganization of priorities and the considerable adjustment in family routines and extra demands placed on family members. Acknowledge the "work" of caring for all family members. Review resources that would free family members to spend more time with the patient.
Preparing for death	Assess your own comfort level in talking about the inevitability of death, describing the dying process, and helping families make plans for wills and funerals. Realize that family members will vary in their ability to assimilate the changes and that a range of reactions and coping strategies is normal. Provide information about the dying process.
Struggling with paradox	Discuss patients' preferences about the circumstances of their death. Encourage patients to discuss these issues with their family. Acknowledge how difficult such discussions can be. Appreciate that you, as a nurse, cannot completely alleviate the psychosocial-spiritual pain inherent in the family's struggle. Assess your own comfort level in working with people facing paradoxical situations and ambivalent feelings. Encourage patients to do important "last things," such as completing a project as a legacy for their family. Provide opportunities for family members to mourn the loss of their hopes and plans. Do not minimize these losses; help them modify their previous hopes and plans and consider new ones. Provide opportunities for spouses and children to express their concerns about their future without the patient. Provide them with opportunities to reminisce about their life together. Acknowledge that such remembrances will have a bittersweet quality. Listen to their expressions of ambivalence, and be prepared for the ups and downs of opinions.

Source: Davies et al. (1995).

which includes fatigue and physical exhaustion, sleeplessness, and deterioration of health.[50] Social burdens encompass limited time for self and social stress related to isolation.[46] Financial burdens, reported as the costs of caring for a person at the end of life, are substantial.[55] Despite the burdens and challenges reported by many family caregivers, research shows that many caregivers continue to want to provide palliative care even when the experience becomes burdensome and overwhelming for them.[58]

Family Caregiver Quality of Life

Family caregivers identify that they are better able to cope with their caregiving roles when their QOL concerns are addressed and their needs are attended to. Family caregivers are diverse, and what is important to QOL at an individual level will vary greatly from person to person and even for the same person over time. Research shows, however, that there are some commonalities in what family caregivers say is important to their QOL. Cohen and colleagues[59] identified seven dimensions that family caregivers identify as important to their QOL:

1. *The state of the family caregiver*: Physical well-being, mental health, being able to think clearly and think of something other than the patient's illness and a sense of feeling in control;
2. *Their family member's condition*: When the patient has a good day, the family caregiver also has a good day;
3. *Their environment*: When family caregivers believe that their significant other is in the best place, be that at home, at the hospital, or other facility, and having privacy when they want it;
4. *The family caregiver's outlook on life*: When life has meaning, when faith and spirituality is comforting, and when providing care to their significant other is rewarding;
5. *Healthcare*: The family caregiver is comfortable with the way that decisions are made for their family member and is satisfied with the care their family member receives and how they are both treated by the healthcare team;
6. *Relationships*: That they have a relationship with the person they are caring for and with other people that are important to them; and
7. *Financial concerns are addressed and not negatively affecting their life*.

Family caregiver QOL is associated with the extent to which family caregivers perceive that their and the patient's needs are met.[60] Family caregivers have many needs related to both their own well-being and that of the patient. It is important that they focus on meeting both types of need. If they focus only on meeting their needs related to caring for the patient and neglect to take care of themselves, then they are likely to become unable to continue providing care, either because they become ill themselves or become overwhelmed.[61,62] *Their own health and well-being is just as important as that of the patient.* Some common needs found in studies of family caregivers are summarized in Table 32.2. Though they may not apply to all family caregivers in palliative care, it is important that these needs are taken into consideration when conducting family caregiver assessment.

Family Caregiver Assessment in Palliative Care

In both practice and research, palliative care has had the majority of its focus centered on families affected by cancer.[1–3,5–7,12] Yet in the past several years, a number of organizational reports, research priority papers, organizational statements, and reviews of the literature have synthesized and catalogued the state of the science of family caregiving generally[13,15,17,65–68] and within the context of serious non-cancer illnesses, including dementia and Alzheimer's disease,[36,37] heart failure and stroke,[63,69–71] kidney disease,[34,35] lung disease/chronic obstructive pulmonary disease (COPD),[28,33] and pediatric serious illness.[72,73] There can be several differences in the caregiving experience that are attributed to these specific illnesses. These differences can include the duration and intensity of caregiving (e.g., cancer caregiving tends to be of relatively short duration but very intense),[7] the types of treatment decisions faced (e.g., heart failure caregivers often assist with decisions about mechanical circulatory support device placement or pacemaker deactivation[69]), and special challenges due to a care recipient's cognitive impairment (e.g., dementia caregivers dealing with their care recipient's deteriorating sense of self). Hence, palliative care nurses are encouraged to review these cited resources for their respective areas of practices.

Despite these and other differences in the caregiving experience that may be characteristic of specific serious illnesses, there are common elements of assessment that the palliative care nurse should consider. Family caregiver assessment is important because research has found that nurses tend to focus on the patient, tend not to undertake comprehensive screening of family caregivers, and may be reluctant to openly do so in the patient's presence.[74] Without having a comprehensive understanding of the support needs of family caregivers, nurses' capacity to provide assistance is limited. The following points summarize these elements and are based on published guidelines and other texts.[75]

- An initial comprehensive assessment should be initiated when a patient is first diagnosed with serious, potentially incurable illness, even if disease-modifying and curative therapies remain the focus of medical treatment.
- Caregiver assessment should be tailored to an institution's resources, setting, and culture and yet result in a plan of care that is determined collaboratively with the family and that has measurable objectives of success.
- The purpose of caregiving assessment should ideally include (but not be limited to): (1) identifying the primary caregiver and other family members who assist with caregiving tasks, (2) assessing caregivers' physical and psychological health, (3) understanding the demands that the patient's illness is likely to place on the family, and (4) determining the capacity of the family to meet these demands.
- Assessment might also include what caregivers understand about how their patient's illness and its progression may impact their lives in the future. What have they discussed with the patient concerning advance care planning? Have they talked about surrogate decision-making?
- The history of the caregiver–care recipient relationship can be a significant determinant of how family members cope with the caregiver role. Not all family members will take on a caregiving role willingly, and hence this should be assessed.
- Assessment findings should be used to provide caregivers with educational materials relevant to immediate priorities and expressed concerns and to link caregivers to existing resources and community services. Family carers with assessment findings indicating clinically significant physical or mental health changes due to caregiving should be referred to a specialized professional or service.

Table 32.2 The needs of family caregivers in palliative care

Maintaining a balance	
Family caregivers' own needs	**Needs to be able to provide care for the patient**
Physical Maintain physical health Strength to provide care Sleep Rest *Psychological* Cope with strong and difficult emotions Maintain mental health Manage anxiety Avoid depression Be supported emotionally Maintain self-esteem Recognition of their anticipatory grief *Cognitive* Maintain cognitive functioning Get a mental break from caregiving and the illness Have privacy *Existential/spiritual* Retain hope Feel in control Find meaning in their new situation Strength from spirituality/faith Feel reward from caregiving Prevent isolation *Social* Financial security Learn new roles Be helped with other roles Cultural needs/differences to be respected	*Information* Obtain and understand information about patient's condition Feel prepared to provide care *Healthcare* Healthcare team to be competent Healthcare team to be available Access to assistive devices Be comfortable with the way they are involved in decisions for the patient's care *Relationships* Appreciation of their caregiving Have a good and trusting relationship with the patient Have a good and trusting relationship with the healthcare team *Environment* Have modifications made to the home Have a safe environment *Psychological* Feel confidence in their caregiving ability/role *Taught how to and/or help with* Administer medications through numerous routes (i.e., injections, suppositories, oxygen masks, etc.) Move and position the patient Be able to safely toilet, feed, and transfer the patient from one position to another Monitor/assess Emotionally support patient Household tasks (they are increased) Coordinate and navigate care Organize Ask others for help Access available financial benefits Transport the patient and themselves if patient is not living at home Plan for death

Source: Stajduhar & Cohen, 2008.

- Caregivers should be reassessed at regular intervals, including any time there is an acute change in the care recipient's health status, a care recipient transition in living situation or care setting, and prior to major treatment decisions (e.g., heart transplant, continue or discontinue dialysis).
- Caregiver assessment should be driven by a conceptual framework.

Tools to assist in the assessment of family caregiver support needs exist in the literature.[76,77] One recent example is the Carer Support Needs Assessment Tool (CSNAT) developed by researchers in the United Kingdom.[26] The CSNAT consists of 14 questions and can be used by nurses as a screen to identify family caregivers' key support needs that require further assessment. The tool is designed both to help legitimize family caregiver needs for support to family caregivers themselves and to make such needs visible and explicit to nurses and other health professionals. It focuses on support domains that enable the family caregiver to care for the patient ("Do you need more support with . . . understanding your relative's illness? Managing your relative's symptoms, including providing medicines? Providing personal care for your relative?

Knowing who to contact if you are concerned about your relative? Equipment to help care for your relative? Talking with your relative about his or her illness? Knowing what to expect in the future when caring for your relative?") and on more direct support domains for family caregivers themselves (i.e., "Do you need more support with . . . Having time for yourself in the day? Your financial, legal, or work issues? Dealing with your feelings and worries? Looking after your own health (physical problems)? Your beliefs or spiritual concerns? Practical help in the home? Getting a break from caregiving overnight?"). In addition to the 14 questions assessing family caregivers' needs for support, the tool includes one optional additional question to capture anything that might not have been addressed.

Supporting Family Caregivers in Different Settings

While the majority of care that families provide is in the home, there are many different settings where family caregivers play a critical role. The following sections describe the roles that caregivers can play in different settings, and general guidance is provided for the palliative care nurse on how to best prepare and support family members in these different settings.

In the Home

For family members of patients with advanced illnesses, family members have been reported to provide support an average of 8 hours per day for community-dwelling relatives in the home.[78] The tasks that are performed include routine tasks such as meal preparation, housework and lawn maintenance, managerial and financial tasks, transportation, and care for other family members. While some of these routine tasks may have already been part of the family member's normal daily routine, others may have been formerly managed by the patient until he or she became too sick to assume these tasks. Other tasks involve medical/nursing and hands-on patient care. These tasks might include healthcare and medical appointment coordination, emotional and spiritual support, medication management and administration, wound and medical device care, symptom monitoring and management, assistance with instrumental and other activities of daily living, promotion of care recipient self-care (e.g., physical activity), and healthcare decision-making. A large survey conducted in the United States found that just 14% of family members had received some kind of training to perform these medical/nursing tasks.[7]

The fundamental challenge that the palliative care nurse can help families with as they care for relatives with serious illness in the home is how to balance the additional demands of caregiving, their paid work, family life, and their own needs. This can be facilitated by helping caregivers make lists of their tasks and responsibilities and identify which tasks are absolutely necessary to accomplish and maintain. The next step is to help the family member estimate how much time each task takes. The family member then has three options to accomplish these tasks: (1) do the task(s) themselves, (2) ask and organize help from other family members and friends, or (3) hire outside assistance. If the caregiver decides to do the task themselves, assess how competent they are in doing the task and encourage them to acquire additional training if needed. For employed caregivers, there may be opportunities for leave, both paid and unpaid. A second option is to rally the assistance of family and friends. It can be difficult for caregivers to ask for volunteer assistance, and so it should be emphasized to caregivers that most family members and friends appreciate the opportunity to be helpful. The palliative care nurse can help caregivers make a list of the family and friends who could offer assistance and urge them to ask for help with specific tasks. A third option for families with the financial means is to hire someone or an agency to assist with tasks in the home. Different ways to find services to meet specific needs include referrals through the patient's provider or social worker, contacting a hospital's patient services department, searching the Internet, and asking family, friends, and community groups for recommendations.

Another particular issue of family caregiving for the palliative care nurse to be aware of are the preferences and special considerations for caregivers providing in-home care at end of life. Deciding to provide home care for relatives at end of life can have a profound effect on family caregivers. Many caregivers believe that providing home care for their loved one is the only option. Some make uninformed decisions, giving little consideration to the implications of their decision. Such decisions are often made early in the patient's disease trajectory or when the patient is imminently dying and may be influenced by the unrealistic portrayal in the media about dying at home. The patient's needs and wishes often drive decisions, with caregivers paying little attention to their own needs. Negotiated decisions for home care typically occur if caregivers and patients are able to talk openly about dying and have done so throughout the disease trajectory. For some families, a home death can bring additional burdens, worries, and responsibilities, so it is important that open discussion be facilitated. Large variations exist in the provision of home-based palliative and EOL care, although the development of hospice home services has enabled increasing numbers of seriously ill patients to experience care at home. Indeed, dying at home has been cited as the preference of the majority of patients, and studies of QOL at end of life have shown home deaths to be associated with higher quality death and dying. However, dying at home can present special challenges for family members. Clinicians must recognize the emotional impact of providing palliative care at home and must be sensitive to the potentially overwhelming task that caring for a dying relative imposes on family members. Care should be provided within a team context so that families understand that they are not alone in supporting the care recipient at end of life in the home and have access to a range of services from the palliative and hospice care team when needed. Furthermore, clinicians must work with the dying patients, with family caregivers, and with each other as equal partners in the caregiving process. Importantly, ongoing attention should be paid to improving hospital EOL care so that families feel they have a meaningful alternative to home care.

In the Hospital

Family caregivers play critical roles when their care recipients with advanced illness are admitted as inpatients into the hospital. They function as the patient's primary advocate, often having a close relationship to the patient that affords them an enhanced understanding of the patient's interests and values. Family caregivers are often present with patients over their illness trajectories and across settings. Hence, they are prime historians and "experts" in the patient's past and ongoing treatments and will often be a co-spokesperson with the patient in their encounters with different healthcare professionals. Though typically relieved of providing medical and nursing tasks while patients are in the hospital, family caregivers will often continue to provide essential companionship and emotional and spiritual support to patients. When appropriate, families may also provide hands-on patient care assistance such as bathing, dressing, hygiene, and feeding. And, finally, caregivers play an essential role in the discharge and transition-of-care process. To ensure patients continue to receive high-quality care after leaving the hospital, it is critical that families are prepared to assume and coordinate duties that patients cannot do for themselves but are made necessary by their medical condition and functional status.

For palliative care nurses interacting with families in the hospital, there are a few general principles to offering support that promotes their resiliency in the face of what can be a very intimidating and stressful event for them. First and foremost and unless otherwise directed by the patient, include family caregivers in all discussions with the patient about their condition, treatments, and tests. Treat them as partners in the patient's care. Clinicians should be aware that their own attitudes about the involvement of families in the care of patients is critical; if families feel they are a "nuisance" to healthcare providers, they will often become less cooperative with and more resentful of the healthcare system (which may ultimately negatively impact the patient). Second, help orient caregivers to what the different roles are of the different healthcare professionals. Many families may never have heard of palliative care or may associate it with hospice care or death and dying. It is important to convey that palliative care is not terminal illness care but instead serious illness care that is focused on providing an extra layer of support by offering relief from symptoms, pain, and the stress of serious illness. Finally, encourage caregivers to keep a small notebook whenever they talk with a member of the palliative care team. Family members should be reassured that nothing is trivial. All questions are important, and all observations are valuable. They should be encouraged to say when they do not understand something and to ask for information to be repeated as necessary. Palliative care professionals can help by spelling words that family members do not understand or by jotting down explanations. They should reassure family members that asking for help is not a sign of failure, but rather a sign of good common sense. Following such simple guidelines helps keep families from feeling overwhelmed.

In the Intensive Care Unit

Many family caregivers will experience seeing their care recipients in the intensive care unit (ICU) where the most invasive and aggressive medical treatments are performed. What caregivers do in the ICU is similar to what they might be seen doing in the hospital setting, and yet there are differences of relevance for the palliative care clinician. Studies report that family members in the ICU can be under marked psychological duress due to seeing their critically ill relative unconscious and connected to machines, having limited visitation to the patient, witnessing invasive procedures, experiencing distressing uncertainty, and being physically exhausted.[79] Being under such duress can challenge the ability of family members to cognitively process information,[80] and yet they are often asked to speak on behalf of patients' interests, participate in family meetings, and perform as surrogate decision-makers. A palliative care priority in interacting with family members in the ICU is the delivery of honest, easily understandable, and timely information as poor communication has been reported by families as the most frequent complaint in the ICU.[81] Families need to have their emotions and feelings acknowledged by clinicians, to have reassurance that everything is being done to help the patient, and have as liberal access to the patient's bedside as is possible, and they most generally want to know the patient's prognosis.[82] Palliative care nurses interacting with families in the ICU should become familiar with resources that further elaborate best practices for ICU communication skills,[83] conducting family meetings,[84] delivering prognosis,[85] and dealing with family emotions.[86,87]

In the Perioperative Setting

Regardless of whether a patient's surgery is planned or emergent, the perioperative experience for family caregivers can be physically and psychologically exhausting and manifest a range of intense emotions, including uncertainty, fear, and anxiety.[88] A prospective cohort study by Juarez et al.[88] of family caregivers of patients undergoing palliative surgery identified a number of ways that nurses can support families. These included (1) identifying any physical or psychological limitations of family members caring for patients after discharge, (2) educating families on patient postoperative symptom management, (3) ascertaining the caregiver's prior experiences with supporting the patient, (4) initiating referral for suspected psychosocial issues (e.g., depression, financial strain) or spiritual needs, (5) discussing anticipated out-of-pocket costs, (6) communicating patient needs after discharge that will require assistance from the caregiver, and (7) discussing distance and access to care for return visits and urgent care. Prospectively addressing caregiver distress related to uncertainty may be helped by informing families as early as possible about exactly what to expect before, during, and after surgery.[89] Offering support to family members by palliative care-trained nurses may be especially important in situations where the surgery was unexpected or emergent; the surgery is potentially futile or inappropriate; if there are complicated family dynamics; if family members are functionally debilitated, burned out, distressed, or depressed; if there are actual or foreseen ethical dilemmas; if there is expected to be complicated postoperative home-care requiring intense symptom and medication management; and any time it would be unsurprising if the patient became deceased within a year despite surgery.[90]

The Caregiver's Role in Decision-Making and Advance Care Planning

The effects of serious illness on the day-to-day lives of patients and their families inevitably gives rise to new problems and challenges where choices have to be made about the best course of action. Some of these decisions are treatment-related, such as deciding about whether or not to pursue an investigational new chemotherapy or whether to pursue a heart transplant. Others are wellness-related, such as deciding to engage in an exercise program or to change one's diet to reduce symptoms. Other decisions have little to do with health per se, but are imposed upon patients and families by the serious illness, such as whether to hire outside help to assist in the home, whether to sell a business to pay for medical expenses, whether to relocate the patient to a different care setting (e.g., home to assisted living or patient's home or caregiver's home), and even whether to give away a pet because the patient has become too ill to care for it.

In all these decisions, family caregivers play two key roles. First, they act as decision partners with patients who still have the ability to make decisions for themselves. In some cases, patients even regard their family members and sometimes even community members (e.g., pastors) as co-decision-makers along with them. For decisions about medical treatments, studies have reported that family members often help patients comprehend their medical situation, prognosis, and treatment options; are key communicators

Table 32.3 Family caregiver resources for palliative care nurses

Advance care planning/Decision-making/Planning for the future	
Advance Care Planning Australia	https://www.advancecareplanning.org.au/
Get Your Stuff Together	www.gyst.com
Gold Standards Framework: Advance Care Planning	http://www.goldstandardsframework.org.uk/advance-care-planning
Patient Decision Aids	Decisionaid.ohri.ca\AZlist.html
Planning Ahead for the End of Life	https://www.nhs.uk/Planners/end-of-life-care/Pages/planning-ahead.aspx
PREPARE for your care	www.prepareforyourcare.org
Speak Up	www.advancecareplanning.ca
The Conversation Project	www.theconversation.org
Family caregiver resources	
AARP (American Association of Retired Persons): Caregiving	https://www.aarp.org/caregiving/
American Psychological Association – Caregiver Briefcase	http://www.apa.org/pi/about/publications/caregivers/
Caregiver Action Network	www.caregiveraction.org
Carers Australia	http://www.carersaustralia.com.au/
Carers Canada	http://www.carerscanada.ca/
Carers UK	www.carersuk.org
Caring.com	www.caring.com
Family Caregiver Alliance	https://www.caregiver.org/
Lotsa Helping Hands	www.lotsahelpinghands.com
National Alliance for Caregiving	www.caregiving.org
Next Step in Care	www.nextstepincare.org
Palliative and hospice care	
Hospice UK	https://www.hospiceuk.org/
National Hospice and Palliative Care Organization	www.caringinfo.org
Palliative Care Australia	http://palliativecare.org.au/im-a-carer/
The National Council for Palliative Care	http://www.ncpc.org.uk/
Virtual Hospice	http://www.virtualhospice.ca/
Grief and bereavement support	
AARP: Caregiving Grief & Loss	https://www.aarp.org/home-family/caregiving/grief-and-loss/
CarersUK – Bereavement	https://www.carersuk.org/help-and-advice/practical-support/when-caring-ends/bereavement
Dying Matters	http://www.dyingmatters.org/
Family Caregiver Alliance - Grief and Loss	https://www.caregiver.org/grief-and-loss
National Cancer Institute – Grief, Bereavement, and Coping with Loss	https://www.cancer.gov/about-cancer/advanced-cancer/caregivers/planning/bereavement-pdq
Virtual Hospice - My grief	http://www.mygrief.ca/
Information on specific illnesses	
ALS Association	http://www.alsa.org/als-care/caregivers/for-caregivers.html
Alzheimer's Association	https://www.alz.org/care/
American Heart Association	http://www.heart.org/HEARTORG/Support/ Support_UCM_001103_SubHomePage.jsp
MS Society of Canada	https://mssociety.ca/support-services/caregivers/information-and-resources
National Cancer Institute	https://www.cancer.gov/about-cancer/coping/caregiver-support
National Kidney Foundation	https://www.kidney.org/patients/resources_Caregiver

and coordinators with providers during office visits where treatment decisions are made; and trigger help-seeking decisions when symptoms worsen.[91] For both healthcare and non-healthcare decisions, family caregivers are information gatherers and holders who often seek out and gather information about available options and the pros and cons of a decision. This can give family caregivers a great deal of influence because they are able to selectively seek out and relay information that consciously or unconsciously favors their own values and preferences. Family caregivers are also the individuals most proximally impacted by the consequences of patient decisions and, in this sense, have a vested stake in the choice selected and the outcome incurred. Evidence suggests that patients themselves are sensitive to this and often weigh decisions about palliative care and life-sustaining treatments based on how much they feel they are burdening family caregivers with their healthcare decisions and care.[92,93]

The second key role that caregivers play in the decision-making of patients is as a surrogate decision-maker when patients become unable to make decisions for themselves, often at end of life. Whether care is provided in the hospital or by families in the home or at a distance, patients at the end of life may not be able to make decisions about their own care. Family members, therefore, are often asked to make those decisions on the patient's behalf according to ethical standards of *concordance*, which require that decisions approximate as closely as possible those choices the patient would have made if they had been able.[94] These decisions are often about (though not limited to) the withdrawal or withholding of life-sustaining treatments such as mechanical ventilation, dialysis, and vasopressor support. A few challenges have been noted for family members in this role, including that the role itself can be extraordinarily burdensome and is often associated with negative psychological aftereffects that may persist for months to years after the death of a patient.[95] These psychological aftereffects can include depression, anxiety, and guilt about whether or not the "right" decision was made. Surrogates have also been repeatedly shown to be poor predictors of patients' treatment preferences.[96]

Many of the difficulties encountered in surrogate decision-making are related to family members not knowing what the patient would want. The palliative care clinician is thus urged to involve family members and their patients as early as possible in advance care planning. *Advance care planning* is a process that allows the patient's preferences to be made known to the family and to healthcare professionals. It involves discussions between the patient and his or her family and friends, as well as written instructions in the event that a patient can no longer express his or her choices verbally. Advance care planning is best begun while family members are healthy, but, when someone is ill, then as early as possible in the illness experience and revisited as needed because preferences can change over time. However, even in the less than 30% of cases when an adult has an advance directive, it may be neither specific enough nor available when needed. Clinicians should ask if advance directives are available, and they might invite family discussion regardless of whether or not such directives are in place. It is important for clinicians to be familiar with a patient's advance directive and to advocate for the patient if needed.

Recognizing the family caregiver's involvement in decision-making is critical to helping patients achieve their goals and receive care that is reflective of their values. When family members are involved in the advance care planning and decision-making process, they are more likely to work toward helping the patient achieve their preferences. Clinicians should be available to families, offering anticipatory guidance and support through the caregiving experience. Healthcare professionals must assist family members as they traverse the maze of treatment and care decisions, ranging from whether to give particular "as needed" medications, or what food to make for the patient to eat, to whether or not to seek hospice care, to sign "do-not-resuscitate" documents, or to terminate treatment. It is critical that palliative care professionals continually engage with caregivers in forward planning, interpretation, and monitoring of the inevitable decline and dying process of the ill person to facilitate the feeling in caregivers that they are secure and supported in their physically and emotionally exhaustive work. Families need to know whom to call and when, and how to reach them. Table 32.3 provides information on various resources available for family caregivers; palliative care nurses can supplement this table with local resources and service agencies.

Conclusion

The primary goal of palliative care is to improve the QOL and quality of death of dying people and their families through provision of excellent care. Families share most intimately the experience of living with and dying from a terminal illness. They are strongly affected, both positively and negatively. Many also wish to provide care for their loved one, but they require support from nurses and others in the healthcare team to do so without being overburdened and endangering their own health and well-being. Nurses play a key role in helping families to navigate uncharted territory, in identifying the family's needs for support, and in assessing and personalizing a plan of care not only for the patient but for the family as a whole and its individual members. While not all families generate positive benefits from the experience of losing a loved one, many families and family caregivers derive significant meaning from the experience of supporting another in the palliative phases of care.

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CHAPTER 33

Planning for the Actual Death

Patricia Berry and Julie Griffie

Key Points

- The care of patients near death and their families and the care afterward is an important nursing function—arguably one of the most important things nurses do.
- At the end of life, there are no dress rehearsals; nurses and other healthcare professionals only have one chance to "get it right."
- Assessment and aggressive management of symptoms must remain a priority, especially as death approaches.
- As the person nears death, the goals of care inevitably change in rhythm with patient and family needs and wishes. The nurse is key in picking up the rhythm of the situation and considering the perspectives and needs of everyone involved, assuring the best experience possible for all.
- Care of the body after death, including normalizing and interpreting postmortem changes and honoring rituals and individual requests, is critically important in communicating to family members and close others that the person who died was indeed important and valued.

Introduction

Issues and needs at the time of death are exceedingly important and, at the same time, exceptionally personal. While the physiology of dying is often the same for most expected deaths, the psychological, spiritual, cultural, and family issues are as unique and varied as the patients and families themselves. As death nears, the goals of care must be discussed and appropriately redefined. Some treatments may be discontinued, and symptoms may intensify, subside, or even appear anew. Physiological changes as death approaches must also be defined, normalized, explained, and interpreted to the patient whenever possible, as well as to the patient's family, close others, and caregivers. The nurse occupies a key position in assisting patients' family members at the time of death by supporting and/or suggesting death rituals, caring for the body after death, and facilitating early grief work. In past literature, most of the focus on death and dying has been on the dying process in general, making the need for a chapter focused specifically on the actual death—and the time right before and after—even more important for a discussion on the role of the palliative nurse during this experience.

Terminally ill persons are cared for in a variety of settings, including home settings with hospice care or traditional home care, hospice residential facilities, nursing homes, assisted living facilities, hospitals, intensive care units, prisons, and group homes. Deaths in intensive care settings may present special challenges, such as restrictive visiting hours and lack of space and less privacy for families—shortcomings that can be addressed by thoughtful and creative nursing care. Likewise, death in a nursing home setting may also offer unique challenges. Regardless of the setting, anticipating and managing pain and symptoms can minimize distress and maximize quality of life. Families can be supported in a way that optimizes use of valuable time and lessens distress during the bereavement period. Health professionals only have one chance to "get it right"—to do the right thing at the time rather than trying to go back and correct something when caring for dying persons and their families as death nears. This is especially true during the final hours before death. In other words, there is no dress rehearsal for the time surrounding death; anticipation of common symptoms and careful, thoughtful, and extensive planning ensures the least stressful and best possible outcome for all involved.

The patient's family is especially important as death nears. Family members may become full- or part-time caregivers; daughters and sons may find themselves in a position to "parent" their parents; and family issues, long forgotten or ignored, may surface. Although "family" is often thought of in traditional terms, a family may take on several forms and configurations. For the purposes of this chapter, the definition of family recognizes that many patients have nontraditional families and may be cared for by a large extended entity, such as a church community, a group of supportive friends, or the staff of a healthcare facility. Family is defined broadly to include not only persons bound by biology or legal ties but also those whom the patient defines or who define themselves as "close others" or who function for the patient as a family member would, including the provision of nurturance, intimacy, and economic, social, and psychological support in times of need; support in illness (including dealing with those outside the family); and companionship.

The occurrence of symptoms at end of life is temporal in nature; that is, there is a constellation of symptoms common throughout the course of end-stage disease and symptoms that appear during the period immediately preceding death, most often 2–3 days prior. As death nears, symptoms can escalate and new ones appear. While there is much known about the assessment and management of symptoms near death, most research demonstrates that many people experience a death with symptoms not well controlled.[1] In a systematic review of signs of impending death and symptoms in the last 2 weeks of life, a total of 43 symptoms were identified, with dyspnea (56.7%), pain (52.4%), noisy breathing/respiratory congestion (51.4%), and confusion (50.1%) as the most common.[2] Within a few days of death, many patients experience a higher frequency of noisy and moist breathing, urinary incontinence and retention, restlessness, agitation, delirium, and nausea and vomiting.[1–4] Symptoms that occur with less frequency include sweating and myoclonus, with myoclonus sometimes occurring as a reversible toxic effect of opioids, most notably morphine, especially in older adults and those with renal impairment.[2,3,5] In most studies, symptoms requiring maximum diligence in assessment, prevention, and aggressive treatment during the final day or two before death are respiratory tract secretions/moist breathing, pain, dyspnea, and agitated delirium, which is very common.[2–4] For some patients, the path of dying is characterized by progressive sleepiness leading to coma and death. For others, the pathway to death is marked by increasing symptoms, including restlessness, confusion, hallucinations, sometimes seizure activity, and then coma and death.[6,7] Assessment and intervention is focused on identifying those persons who are on the more difficult pathway and aggressively treating their symptoms to assure a peaceful death. Persons with cognitive impairment and the inability to self-report or communicate require specific attention to symptoms, especially as death nears. In any case, the nurse plays a key role in assessing and anticipating symptoms, acting promptly to assure, if at all possible, that symptoms are aggressively prevented and managed before they become severe. The nurse also has an important role in educating family members and other caregivers about the assessment, treatment, and ongoing evaluation of these symptoms.

Regardless of individual patient and family needs, attitudes, and "unfinished business," the nurse's professional approach and demeanor at the time near death is crucial and worthy of close attention. Patients experience total and profound dependency at this stage of their illness. Families are often called on to assume total caregiving duties, often disrupting their own responsibilities for home, children, and career. Although there may be similarities, patients and families experience this time through the unique lens of their own perspective and form their own unique meanings.

Some authors suggest theories and guidelines to help support the nurse in establishing and maintaining meaningful, helpful, and therapeutic relationships with patients or clients and their families. One example is Carl Rogers's theory of helping relationships, in which he proposed that the characteristics of a helping relationship are empathy, unconditional positive regard, and genuineness.[8] These characteristics, defined later as part of the nurse's approach to patients and families, are essential in facilitating care at the end of life. To this may be added "attention to detail," as this additional characteristic is widely accepted as essential for individualized, patient- and family-centered, quality palliative care.[9] Readers are urged to consider the following characteristics as they reflect on their own practice because they can serve as a powerful foundation for facilitating and providing supportive relationships:

- *Empathy*: The ability to put oneself in the other person's place, trying to understand the patient or client from his or her own frame of reference; it also requires the deliberate setting aside of one's own frame of reference and bias.
- *Unconditional positive regard*: A warm feeling toward others, with a nonjudgmental acceptance of all they reveal themselves to be; the ability to convey a sense of respect and esteem at a time and place in which it is particularly important to do so.
- *Genuineness*: The ability to convey trustworthiness and openness that is real rather than a professional facade; also the ability to admit that one has limitations, makes mistakes, and does not have all the answers.
- *Attention to detail*: The learned and practiced ability to think critically about a situation and not make assumptions. The nurse, for example, discusses challenging patient and family concerns with colleagues and other members of the interdisciplinary team. The nurse considers every "what if" before making a decision and, in particular, before making any judgment. Finally, the nurse is constantly aware of how his or her actions, attitudes, and words may be interpreted—or misinterpreted—by others.

The events and interactions—positive as well as negative—that occur at the bedside of a dying person set the tone for the patient's care and form lasting memories for family members. The time of death and the care received by both the individual who has died and the family members who are present are predominant aspects of the survivors' memories of this momentous event. Approaching patients and families with a genuine openness characterized by empathy and positive regard eases the way in making this difficult time meaningful, individualized, and deeply profound.

This chapter discusses some key issues surrounding the death itself, including advance planning and the evolving and ever-changing choices and goals of care, the changing focus of care as death nears, common signs and symptoms of nearing death and their management, and care of the patient and family at time of death. It concludes with two case examples illustrating the chapter's content.

Advance Planning: Evolving Choices and Goals of Care

Healthcare choices related to wellness are generally viewed as clear-cut or easy. We have an infection, we seek treatment, and the problem resolves. Throughout most of the life span, medical treatment choices are obvious. As wellness moves along the healthcare continuum to illness, choices become less clear, and the consequences of choices have a significantly greater impact.

Many end-of-life (EOL) illnesses manifest with well-known and well-documented natural courses. Providing the patient and family with information on the natural course of the disease at appropriate intervals is a critical function of healthcare providers such as nurses. Providing an opening for discussion, such as, "Would you like to talk about the future?" "Do you have any concerns that I can help you address?" or "It seems you are not as active as you were before," may allow a much-needed discussion of fears and concerns about impending death. Family members may request information that patients do not wish to know at certain points in time. With the patient's permission, discussions with the family may occur in the patient's absence. Family members may also need coaching to initiate EOL discussions with the patient. EOL goal-setting is greatly enhanced when the patient is aware of the support of family.

EOL care issues should always be discussed with patients and family members. The patient who is capable of participating in and making decisions is always the acknowledged decision-maker. The involvement of family ensures maximal consensus for patient support as decisions are actually implemented. Decisions for patients who lack decision-making capacity should be made by a consensus approach, using a family conference methodology. If documents such as a durable power of attorney for healthcare or a living will are available, they can be used as a guide for examining wishes that influence decision-making and goal-setting. The decision-maker, usually the person named as healthcare power of attorney (HCPOA), or the patient's primary family members, should be clearly identified. This approach is also useful with patients who are able to make their own decisions and, of course, should always include the patient as a participant.

To facilitate decision-making, convening a family conference that involves the decision-makers (decisional patient, family members, and the HCPOA), the patient's physician or provider, nurse, chaplain, and social worker is ideal. A history of how the patient's healthcare status evolved from diagnosis to the present is reviewed. The family is presented with the natural course of the disease. Choices on how care may proceed, including prognostic estimations and the benefits and burdens of treatments, are reviewed. Guidance or support for those choices is provided based on existing data and clinical experience with the particular disease in relation to the current status of the patient. If no consensus for the needed decisions occurs, decision-making is postponed. Third-party support by a trusted individual or consultant may then be enlisted. Decisions by patients and families a cross the spectrum of care range from continuing treatment for the actual disease, such as undergoing chemotherapy or renal dialysis or utilization of medications, to initiating cardiopulmonary resuscitation (CPR). The healthcare provider may work with the patient and family, making care decisions for specific treatments and timing treatment discontinuance within a clear and logical framework. A goal-setting discussion may determine a patient's personal preferences for care, such as:

- Treatment and enrollment in any clinical studies for which the patient is eligible.
- Treatment as long as statistically there is a greater than 50% chance of response.
- Full treatment as long as the patient is ambulatory and able to come to the clinic or office.
- Treatment only of "fixable" conditions such as infections or blood glucose levels.
- Treatment only for controlling symptomatic aspects of disease.

Once a goals of care framework has been established with the patient, the appropriateness of interventions such as CPR, renal dialysis, or intravenous antibiotics is clear. For instance, if the patient states a desire for renal dialysis as long as transportation to the clinic is possible without the use of an ambulance, the endpoint of dialysis treatment is quite clear. At this point, the futility of CPR would also be apparent. Allowing a patient to determine when the treatment is a burden that is unjustified by his or her value system, and communicating this determination to family and caregivers, is a pivotal point in management of the patient's care. There are multiple guidelines and formats for conducting and/or participating in a family conference and the role of the nurse. Box 33.1 suggests one format for an effective and comprehensive family conference.

Box 33.1 Moderating an End-of-Life Family Conference

I. *Why*: Clarify goals in your own mind. For example, what is the purpose of the meeting, who is attending? Gather members of the healthcare team prior to the meeting to assure that everyone is clear on their role and the goals of the conference.

II. *Where*: Provide comfort, privacy, circular seating.

III. *Who*: Include legal decision-maker/healthcare power of attorney; family members; social support; key healthcare professionals, patient if capable to participate.

IV. *How*:

  A. Introduction
    1. Introduce self and others.
    2. Review meeting goals: Review provider-intended goals, elicit patient/family-intended goals, and then negotiate a plan to proceed
    3. Establish ground rules: Each person will have a chance to ask questions and express views; no interruptions; identify legal decision-maker, and describe importance of supportive decision-making.
    4. If new to patient/family, spend some time getting to know the family and the patient as people.

  B. Determine what the patient/family knows and understands.

  C. Review medical status.
    1. Review current status, plan, and prognosis.
    2. Ask each family member in turn for any questions about current status, plan, and prognosis.
    3. Defer discussion of decision until the next step.
    4. Respond to emotions.

  D. Family discussion with decisional patient:
    1. Ask patient, "What decision(s) are you considering?"
    2. Ask each family member, "Do you have questions or concerns about the treatment plan? How can you support the patient?"

  E. Family discussion with nondecisional patient:
    1. Ask each family member in turn, "What do you believe the patient would choose if he (or she) could speak for himself (or herself)?"
    2. Ask each family member, "What do you think should be done?"
    3. Leave room to let family discuss alone.
    4. If there is consensus, go to V; if no consensus, go to F.

  F. When there is no consensus:
    1. Restate goal: "What would the patient say if he or she could speak?"
    2. Use time as ally: Schedule a follow-up conference the next day.

(*continued*)

Box 33.1 Continued

3. Try further discussion: "What values is your decision based on? How will the decision affect you and other family members?"
4. Identify legal decision-maker.
5. Identify resources: minister/priest; other physicians; ethics committee.

V. *Wrap-up*:
  - A. Summarize consensus, decisions, and plan.
  - B. Caution against unexpected outcomes.
  - C. Identify family spokesperson for ongoing communication.
  - D. Document in the chart who was present, what decisions were made, follow-up plan.
  - E. Approach discontinuation of treatment as an interdisciplinary team, not just as a nursing function.
  - F. Continuity: Maintain contact with family and medical team; schedule follow-up meetings as needed.

VI. *Family dynamics and decisions*:
  - A. Family structure: Respect the family hierarchy whenever possible.
  - B. Established patterns of family interaction will continue.
  - C. Unresolved conflicts between family members may be evident.
  - D. Past problems with authority figures, doctors, and hospitals affect the process; ask specifically about bad experiences in the past.
  - E. Family grieving and decision-making may include:
    1. Denial: False hopes, misunderstanding of the situation.
    2. Guilt: Fear of letting go, including regrets.
    3. Depression: Passivity and inability to decide; or anger and irritability.

Source: Adapted from Ambuel B, Weissman D. Fast Fact and Concept #016: Conducting a Family Conference (3rd ed). 2015. Available at https://www.mypcnow.org/blank-qy84d. Accessed November 17, 2017.

Changing the Focus of Care as Death Nears

As death nears, the rhythm of care changes; visiting hours in an institutional setting are relaxed; the routines of care, for example, taking vital signs, tracking intake and output, and daily weights seem less important; and treatments automatically associated with caring for any patient are considered in the context of benefit and burden. Here we focus on some of these routines and treatments, recognizing that the nurse again plays a key role in explaining and normalizing the shifts in the rhythm of care to the patient and family. The nurse also plays an important role in advocating on behalf of the patient, relaying and advocating for the goals of care to colleagues, and assuring that the care delivered is consistent with the goals and preferences of the patient and/or family.

Vital Signs

As nurses, we derive a good deal of security in performing the ritual of measuring vital signs, one of the hallmarks of nursing care. When death is approaching, we need to question the rationale for measuring and recording vital signs. Are interventions going to change if it is discovered that the patient has experienced a drop in blood pressure? If the plan of care no longer involves intervening in changes in blood pressure and pulse rate, the measurements should cease. The time spent taking vital signs can then be redirected to assessment of patient comfort and provision of family support. Changes in respiratory rate are visually noted and do not require routine monitoring of rates, unless symptom management issues develop that could be more accurately assessed by measurement of vital signs. If the patient appears uncomfortable, the measurement of body temperature using a noninvasive route should continue on a regular basis until death. This allows for the detection and management of fever, a frequent symptom that can cause distress and may require management.

Fever often suggests infection. As death approaches, goal-setting should include a discussion of the benefits and burdens of treating an infection. Indications for treatment of infection are based on the degree of distress and patient discomfort.[11] Pharmacological management of fever includes antipyretics, including acetaminophen, and nonsteroidal anti-inflammatory drugs. In some cases, treatment of an infection with an antibiotic may increase patient comfort. Ice packs, alcohol baths, and cooling blankets should be used cautiously because they often cause more distress than the fever itself.[11]

Fever may also suggest dehydration. As with the management of fever, interventions are guided by the degree of distress and patient discomfort. The appropriateness of beginning medically administered hydration for the treatment of fever is based on individual patient assessment, the estimated prognosis, and the goals of care.

Finally, fever may suggest that death is imminent as many people develop a *central fever*; that is, they are cool to the touch but have an increased temperature. In this case, as with all interventions as death nears, treat for patient comfort.

Cardiopulmonary Resuscitation

Patients and family members may need to discuss, if they have not already, the issue of the futility of CPR when death is expected from a terminal illness. Developed in the 1960s as a method of restarting the heart in the event of sudden, unexpected clinical death, CPR was originally intended for circumstances in which death was unexpected or accidental. It is not indicated in certain situations, such as cases of terminal irreversible illness where death is not unexpected; resuscitation in these circumstances may represent an active violation of a person's wish to die on their own terms.

Over the years, predictors of the success of CPR have become apparent, along with the predictors of the burden of CPR. In general, a poor outcome of CPR is predicted in patients with advanced terminal illnesses, patients with dementia, and patients with poor functional status who depend on others for meeting their basic care needs. Poor outcomes or physical problems resulting from CPR include fractured ribs, punctured lung, brain damage if anoxia has occurred for too long, and permanent unconsciousness or persistent vegetative state.[12–13]

Medically Administered Fluids

The issue of medically administered or "artificial" hydration is emotional for many patients and families because of the role that giving and consuming fluids plays in many cultures. When patients are not able to take fluids, concerns may surface among caregivers. A decision must be reached regarding the appropriate use of fluids within the context of the patient's framework of goals. Beginning medically administered hydration is a relatively easy task, but the decision to stop is generally much more problematic given its emotional implications. However, the emotional response attached to withdrawing a treatment adds a world of difference to the decision to suspend. It is therefore much less burdensome to not begin treatment, if this decision is acceptable in light of the specific patient circumstances.[14]

Most patients and families are aware that, without fluids, death will occur quickly. The literature suggests that fluids should not be routinely administered to dying patients, nor automatically withheld from them. Instead, the decision should be based on careful, individual assessment. Zerwekh,[15] in a classic article, suggested consideration of the following questions when the choice to initiate or continue hydration is evaluated. These questions remain relevant today to this important issue:

- Is the patient's well-being enhanced by the overall effect of hydration?
- Which current symptoms are being relieved by medically administered hydration?
- Are other EOL symptoms being aggravated by the fluids?
- Does hydration improve the patient's level of consciousness? If so, is this within the patient's goals and wishes for EOL care?
- Does hydration appear to prolong the patient's survival? If so, is this within the patient's goals and wishes for EOL care?
- What is the effect of the infusion technology on the patient's well-being, mobility, and ability to interact and be with family?
- What is the burden of the infusion technology on the family in terms of caregiver stress or finance? Is it justified by benefit to the patient?

A systematic review from 2014 found insufficient evidence to support the use of medically administrated fluids near the end of life but did note some evidence of hydration reducing sedation and myoclonus.[16] In any case, the uniqueness of the individual situation, the goals of care, the benefits and burdens of the proposed treatment, and the comfort of the patient must always be considered.[17]

Terminal dehydration refers to the process in which the dying patient's condition naturally results in a decrease in fluid intake. A gradual withdrawal from activities of daily living may occur as symptoms such as dysphagia, nausea, and fatigue become more obvious. Families commonly ask whether the patient will be thirsty as fluid intake decreases. Hydration has the potential to cause fluid accumulation, resulting in distressful symptoms such as edema, ascites, nausea and vomiting, and pulmonary congestion.[16]

There is no evidence that rehydration actually prolongs life.[16] Healthcare providers need to assist patients and family members to refocus on the natural course of the disease and the notion that the patient's death will be caused by the disease, not by dehydration, which is a natural occurrence in advanced illness and dying. Nurses may then assist families in dealing with symptoms caused by dehydration.

Dry mouth, a consistently reported distressing symptom of dehydration, can be relieved with sips of beverages, ice chips, or hard candies. Another simple comfort measure for dry mouth is spraying normal saline into the mouth with a spray bottle or atomizer. (Normal saline is made by mixing 1 teaspoon of table salt in a quart of water.) Meticulous mouth care must be administered to keep the patient's mouth clean. Family members can be instructed to anticipate this need. The nurse can facilitate this care by ensuring that the necessary provisions are on hand to assist the patient.

Medications

Medications unrelated to the terminal diagnosis are generally continued as long as their administration is not burdensome. When swallowing tablets or capsules becomes too difficult, the medication may be offered in a liquid or other form if available, considering patient and family comfort. Continuing medications, however, may be seen by some patients and families as a way of normalizing daily activities and therefore should be supported. Considerable tact, kindness, and knowledge of the patient and family are needed in assisting them to make decisions about discontinuing medications.

Medications that do not contribute to daily comfort should be evaluated on an individual basis for possible discontinuance. Medications such as antihypertensives, replacement hormones, vitamin supplements, iron preparations, hypoglycemics, long-term antibiotics, antiarrhythmics, and laxatives, unless they are essential to patient comfort, can and should be discontinued unless doing so would cause symptoms or discomfort. Accordingly, special consideration should be given to the use of diuretics with patients with end-stage heart disease and corticosteroids in patients with neuropathic pain or for the treatment of increased intracranial pressure. While there are no specific guidelines governing this practice, the control or prevention of distressing symptoms should be the guiding principle in the use of medications, especially in the final days of life.[18]

Cardiovascular Implantable Electronic Devices

Cardiovascular implantable electronic devices (CIEDs) are used to prevent cardiac arrest due to ventricular tachycardia or ventricular fibrillation. Patients with CIEDs who are dying of another terminal condition or are withdrawn from antiarrhythmic medications may choose to have the defibrillator deactivated, or turned off, so that there will be no interference from the device at the time of death. If the patient has a CIED, it is critical to confirm its deactivation if that is in keeping with the goals of care. Screening for a CIED in out-of-institution care settings, like hospices, because of the high likelihood of preventable adverse events is critical.[19] The interprofessional guideline, *HRS Expert Consensus Statement on the Management of Cardiovascular Implantable Electronic Devices (CIEDs) in Patients Nearing End of Life or Requesting Withdrawal of Therapy,* provides detailed guidance on the ethical, legal, and practical aspects of CIED deactivation.[20]

Renal Dialysis

Renal dialysis is a life-sustaining treatment, and, as death approaches, it is important to recognize and agree on its limitations. Discontinuation of dialysis should be considered in the following cases:

- Patients with acute, concurrent illness, who, if they survive, will be burdened with a great deal of disability as defined by the patient and family.

- Patients with progressive and untreatable disease or disability.
- Patients with dementia or severe neurological deficit.

There is general agreement that dialysis should not be used to prolong the dying process. The time between discontinuing dialysis and death varies widely, from a matter of hours or days (for patients with acute illnesses, such as those described earlier) to days or a week or longer if some residual renal function remains. While there are clinical practice guidelines and continuing interest in palliative care in end-stage renal disease, opening a discussion about the burden of treatment is a delicate task.[21–24] There may be competing opinions among the patient, family, and even staff about the tolerability or intolerability of continuing treatment. The nurse who sees the patient and family on a regular basis may be the most logical person to recognize the discrete changes in status. Gently validating these observations may open a much-needed discussion regarding the goals of care.

The discussions and decisions surrounding discontinuation or modification of treatment are never easy. Phrases such as, "There is nothing more that can be done" or "We have tried everything" have no place in EOL discussions with patients and families. Always reassure the patient and family members—and be prepared to follow through—that you will stand by them and do all you can to provide help and comfort. This is essential to ensure that palliative care is not interpreted as abandonment.

In addition to addressing concerns the patient and family may have as death nears, the nurse should explore and confirm wishes and preferences for after the patient dies. For example, have funeral arrangements been discussed? Have any decisions been made? Has a funeral provider been selected? Are there any special considerations for eye, tissue, or body donation? The nurse has a pivotal role in encouraging family members to carefully select a funeral provider and to gather information as they would any other provider (for example, a long-term care facility, a healthcare provider). Urge the family, if the choice is not certain, to take the time to call and visit funeral providers before taking advice from others and making a final decision. This is a critical nursing function regardless of the setting of care and the place of anticipated death.

Common Signs and Symptoms of Imminent Death and Their Management

There usually are predictable sets of processes that occur during the final stages of a terminal illness due to gradual hypoxia, respiratory acidosis, metabolic consequences of renal failure, and the signs and symptoms of hypoxic brain function.[1,7] These processes account for the signs and symptoms of imminent death and can assist the nurse in helping the family plan for the actual death.

The following signs and symptoms provide cues that death is only days away[1,7,25]:

- Profound weakness (patient is usually bedbound and requires assistance with all or most care)
- Gaunt and pale physical appearance (most common in persons with cancer if corticosteroids have not been used as treatment)
- Drowsiness and/or a reduction in awareness, insight, and perception (often with extended periods of drowsiness, extreme difficulty in concentrating, severely limited attention span, inability to cooperate with caregivers, disorientation to time and place, or semicomatose state)
- Increasing lack of interest in food and fluid with diminished intake (only able to take sips of fluids)
- Increasing difficulty in swallowing oral medications

During the final days, these signs and symptoms become more pronounced, and, as oxygen concentrations drop, new symptoms also appear. Measurement of oxygen concentration in the dying person is not advocated because it may add discomfort and does not alter the course of care. However, knowledge of the signs and symptoms associated with decreasing oxygen concentrations can assist the nurse in guiding the family as death nears.[25] As oxygen saturation drops below 80%, signs and symptoms related to hypoxia appear. As the dying process proceeds, special issues related to normalizing the dying process for the family, symptom control, and patient and family support present themselves. Table 33.1 summarizes the physiological process of dying and suggests interventions for both patients and families.

As the imminently dying person takes in less fluid, third-spaced fluids, clinically manifested as peripheral edema, ascites, or pleural effusions, may be reabsorbed. Breathing may become easier, and there may be less discomfort from tissue distention. Accordingly, as the person experiences dehydration, swelling is often reduced around tumor masses. Patients may experience transient improvements in comfort, including increased mental status and decreased pain. The family, in this case, needs a careful and compassionate explanation regarding these temporary improvements and encouragement to make the most of this short but potentially meaningful time. There are multiple patient and family educational tools that are widely available to assist families in interpreting the signs and symptoms of approaching death. However, as with all aspects of palliative care, consideration of the individual perspective and associated relationships of the patient or family member, the underlying disease course trajectory, anticipated symptoms, and the setting of care is essential for optimal care at all stages of illness, but especially during the final days and hours.

Care at the Time of Death, Death Rituals, and Facilitating Early Grieving

At the time of death, the nurse has a unique opportunity to provide information helpful in making decisions about organ and body donation and autopsy. In addition, the nurse can support the family's choice of death rituals, gently care for the body, assist in funeral planning, and facilitate the early process of grieving. Family members' needs change around the time of death, just as the goals of care change. During this important time, plans are reviewed and perhaps refined. Special issues affecting the time of death, such as cultural influences, decisions regarding organ or body donation, and the need for autopsy, are also reviewed.

Under US federal law, if death occurs in a hospital setting, staff must approach the family decision-maker regarding the possibility of organ donation.[26] Although approaching family at this time may seem onerous, the opportunity to assist another is often comforting. Some hospital-based palliative care programs include information about organ donation in their admission or bereavement information. Readers are urged to review their own organizations' policies and procedures.

In any case, it is important to clarify specifically with family members what their desires and needs are at the time of death. Do they wish to be present? Do they know of others who wish to now

Table 33.1 Symptoms in the normal progression of dying and suggested interventions

Symptoms	**Suggested interventions**
Early-stage sensation	
Perception	Interpret the signs and symptoms to the patient (when appropriate) and family as part of the normal dying process; for example, assure them the patient's "seeing" and even talking to persons who have died is normal and often expected.
Impairment in the ability to grasp ideas and reason; periods of alertness along with periods of disorientation and restlessness are also noted.	Urge family members to look for metaphors for death in speech and conversation (e.g., talk of a long journey, needing maps or tickets, or in preparing for a trip in other ways) and use these metaphors as a departure point for conversation with the patient.
	Urge family to take advantage of the patient's periods of lucidity to talk with patient and ensure nothing is left unsaid.
	Encourage family members to touch and speak slowly and gently to the patient without being patronizing.
	Maximize safety; for example, use bedrails and schedule people to sit with the patient.
Some loss of visual acuity	Keep sensory stimulation to a minimum, including light, sounds, and visual stimulation; reading to a patient who has enjoyed reading in the past may provide comfort.
Increased sensitivity to bright lights while other senses, except hearing, are dulled	Urge the family to be mindful of what they say "over" the patient because hearing remains present; also continue to urge family to say what they wish not to be left unsaid.
Cardiorespiratory	
Increased pulse and respiratory rate	Normalize the observed changes by interpreting the signs and symptoms as part of the normal dying process and ensuring the patient's comfort.
Agonal respirations or sounds of gasping for air without apparent discomfort	Again, normalize the observed changes by interpreting the signs and symptoms as part of the normal dying process and ensuring the patient's comfort; assess and treat respiratory distress as appropriate
Apnea, periodic, or Cheyne-Stokes respirations	Assess and treat respiratory distress as appropriate.
Inability to cough or clear secretions efficiently, resulting in gurgling or congested breathing (sometimes referred to as the "death rattle")	Assess use and need for parenteral fluids, tube feedings, or hydration. (It is generally appropriate to either discontinue or greatly decrease these at this point in time.)
	Reposition the patient in a side-lying position with the head of the bed elevated.
	Suctioning is rarely needed, but when appropriate, suction should be gentle and only at the level of the mouth, throat, and nasal pharynx.
	Administer anticholinergic drugs (transdermal scopolamine, hyoscyamine) as appropriate, recognizing and discussing with the family that they will not decrease already existing secretions.
Renal/urinary	
Decreasing urinary output, sometimes urinary incontinence or retention	Insert catheter and/or use absorbent padding.
	Carefully assess for urinary retention because restlessness can be a related symptom.
Musculoskeletal	
Gradual loss of the ability to move, beginning with the legs, then progressing.	Reposition every few hours as appropriate.
	Anticipate needs such as sips of fluids, oral care, changing of bed pads and linens, and so on.
Late-stage sensation	
Perception	
Unconsciousness	Interpret the patient's unconsciousness to the family as part of the normal dying process.
Eyes remain half-open, blink reflex is absent; sense of hearing remains intact and may slowly decrease	
	Provide for total care, including incontinence of urine and stool.
	Encourage family members to speak slowly and gently to the patient, with the assurance that hearing remains intact.
Cardiorespiratory	
Heart rate may double, strength of contractions decrease; rhythm becomes irregular	Interpret these changes to family members as part of the normal dying process.

(*continued*)

Table 33.1 Continued

Symptoms	Suggested interventions
Patient feels cool to the touch and becomes diaphoretic	Frequent linen changes and sponge baths may enhance comfort.
Cyanosis is noted in the tip of the nose, nail beds, and knees; extremities may become mottled (progressive mottling indicates death within a few days); absence of a palpable radial pulse may indicate death within hours.	
Renal/urinary	
A precipitous drop in urinary output	Interpret to the family the drop in urinary output as a normal sign that death is near, usually 24–72 hours away.
Carefully assess for urinary retention; restlessness can be a related symptom.	

say a final goodbye? Have they said everything they wish to say to the person who is dying? Do they have any regrets? Are they concerned about anything? Do they wish something could be different? Every person in a family has different and unique needs that, unless explored, can go unmet. Family members recall the time before the death and immediately afterward with great acuity and detail.

Although an expected death can be anticipated with some degree of certainty, the exact time of death is often not predictable. Death often occurs when no healthcare professionals are present. Often, dying people seem to determine the time of their own death—for example, waiting for someone to arrive, for a date or event to pass, or even for family members to leave—even if the leave-taking is brief. For this reason, it is crucial to ask family members who wish to be present at the time of death whether they have thought about the possibility they will not be there. This opens an essential discussion regarding the time of death and its unpredictability. Gently reminding family members of that possibility can assist them in preparing for any eventuality.

Determining that Death Has Occurred

Death often occurs when health professionals are not present at the bedside or in the home. Regardless of the site of death, a plan must be in place for who will be contacted, how the death pronouncement will be handled, and how the body will be removed. This is especially important for deaths that occur outside a healthcare institution.

Death pronouncement procedures vary from state to state and sometimes from county to county within a state. In some states, nurses can pronounce death; in others, they cannot. In inpatient settings, the organization's policy and procedures are followed. In hospice home care, generally the nurse makes a home visit; assesses the lack of vital signs; contacts the physician, who verbally agrees to sign the death certificate; and then contacts the funeral home or mortuary. Local customs, the ability of a healthcare agency to ensure the safety of a nurse during the home visit, and provision for "do-not-resuscitate" orders outside a hospital setting, among other factors, account for wide variability in the practices and procedures surrounding pronouncement of death in the home. Although practices vary widely, the police or coroner may need to be called if the circumstances of the death were unusual, were associated with trauma (regardless of the cause of the death), or occurred within 24 hours of a hospital admission.

The practice of actual death pronouncement varies widely and is not often taught in medical school or residencies. The customary procedure is to first identify the patient, then note the following:

- General appearance of the body
- Lack of reaction to verbal or tactile stimuli
- Lack of pupillary light reflex (pupils will be fixed and dilated)
- Absent breathing and lung sounds
- Absent carotid and apical pulses (in some situations, listening for an apical pulse for a full minute is advisable)

Documentation of the death is equally important and should be thorough and clear. The following guidelines are customary:

- Record the patient's name and time of call.
- Record who was present at the time of death and at the time of the pronouncement.
- Record detailed findings of the physical examination.
- Record the date and time of death pronouncement (either pronouncement by the nurse or the time at which the physician either assessed the patient or was notified).
- Note who else was notified and when—for example, additional family members, attending physician, or other staff members.
- Record whether the coroner was notified, rationale, and outcome, if known.
- Note special plans for disposition and outcome (e.g., organ or body donation, autopsy, special care related to cultural or religious traditions).

Care of the Body after Death

The care of the patient does not end with the death, but rather continues during the immediate postmortem period as the body is prepared for transport into the care of the funeral provider. Regardless of the site of death, therefore, care of the patient's body is an important nursing function. In gently caring for the body, the nurse can continue to communicate care and concern for the patient and family members and model behaviors that may be helpful as the family members continue their important grief work. Caring for the body after death also calls for an understanding of the physiological changes that occur. By understanding these changes, the nurse can interpret and dispel any myths and explain these changes to the family members, thereby assisting the family in making their own personal decisions about the time immediately following death and funeral plans. In the section below and in Table 33.2, we incorporate principles of general funeral practice with information received in conversations with multiple funeral directors.

A classic article regarding postmortem care emphasized that, although postmortem care may be a ritualized nursing procedure, the scientific rationale for the procedure rests on the basics of the physiological changes that occur after death.[27] These changes occur at a regular rate depending on the temperature of the body at the time of death, the size of the body, the extent of infection (if any), the position of the body, and the temperature of the air. The three important physiological changes—*rigor mortis*, *algor mortis*, and *postmortem decomposition*—are discussed along with the relevant nursing implications in Table 33.2.

Care of and respect for the body after death by nursing staff should clearly communicate to the family that the person who died was indeed important and valued. Often, caring for the body after death provides the needed link between family members and the reality of the death, recognizing that everyone present at the time of death and soon after will have a different experience and a different sense of loss. Many institutions no longer require nursing staff to care for patients after death or perform postmortem care. Furthermore, there are very few professional resources related to postmortem care. Those available are outdated and do not reflect knowledge of postmortem changes.[27–31] Research is also limited and either focuses on legal procedures and physical preparation of the body or standardizing care including involving family members.[32–33] Postmortem care, especially in the hospice and palliative care setting, is clearly more than attention to the legal imperatives and physical care. A kind, gentle approach and meticulous attention to detail grounded in knowledge of the physiology of dying and death is imperative. Rituals that family members and others present find comforting should be encouraged. Rituals are practices within a social context that facilitate and provide ways to understand and cope with the contradictory and complex nature of human existence. They provide a means to express and contain strong emotions, ease feelings of anxiety and impotence, and provide structure in times of chaos and disorder. It is the family's needs

Table 33.2 Normal postmortem physiological changes and their implications for nursing and care of the body after death

Change	Underlying mechanisms	Nursing implications
Rigor mortis	Approximately 2–6 hours after death, adenosine triphosphate (ATP) ceases to be synthesized due to the depletion of glycogen stores. Because ATP is necessary for muscle fiber relaxation, the lack of ATP results in an exaggerated contraction of the muscle fibers that eventually immobilizes the joints. Rigor begins in the involuntary muscles (heart, gastrointestinal tract, bladder, arteries) and progresses to the muscles of the eyelids, head and neck, trunk, and lower limbs. After approximately 96 hours, however, muscle chemical activity totally ceases, rigor passes and the muscles will become pliable again. Persons with large muscle mass (e.g., body builders) are prone to more pronounced rigor mortis. Conversely, frail elderly persons and persons who have been bed bound for long periods are less subject to rigor mortis. In this case, muscle chemical activity ceases and rigor passes within 24–96 hours.	The guiding principle is to understand that rigor mortis is a natural and temporary postmortem change and immediate positioning of the decedent does not impact the appearance of the body long term. After death, position the person in as relaxed and peaceful a manner as is possible. For example, gently close the eyes if possible, position the person with the head and shoulders on pillows, and fold the hands. Due to the wide variation of circumstances of the death and the person, there are times when, regardless of position, the jaw will remain open. There is no need, however to mechanically manipulate it or use a towel or small pillow to keep it closed. If rigor mortis does occur, it can often be "massaged out" by the funeral director. Finally, by understanding this physiology, the nurse can also reassure the family about the myth that, due to rigor mortis, muscles can suddenly contract and the body can appear to move. The nurse can also reassure the family that the funeral director is expert in managing and interpreting these normal postmortem changes.
Algor mortis	After the circulation ceases and the hypothalamus stops functioning, internal body temperature drops by approximately 1°C or 1.8°F per hour until it reaches room temperature. As the body cools, skin loses its natural elasticity. If a high fever was present at death, the changes in body temperature are more pronounced and the person may appear to "sweat" after death. Body cooling may also take several more hours.	The nurse can prepare family members for the coolness of the skin to touch or the increased moisture by explaining the changes that happen after death. Also note to the family that their own body heat will transfer from them to the decedent and the place where they touch will feel warm. The nurse may also suggest kissing the person on their hair instead of their skin. The skin, due to loss of elasticity, becomes fragile and easily torn. Do not remove dressings, bandages, and/or tape after the death. If a dressing needs to be applied after death, it is best to secure them using either a circular bandage or paper tape. Remove oxygen masks and nasal prongs; if an endotracheal tube is present facilitate its removal. Handle the body gently as well, being sure to not place traction on the skin.
Postmortem decomposition or "livor mortis"	Discoloration and softening of the body are caused largely by the breakdown of red blood cells and the resultant release of hemoglobin that stains the vessel walls and surrounding tissue. This staining appears as a mottling, bruising, or both in the dependent parts of the body as well as parts of the body where the skin has been punctured (e.g., intravenous or chest tube sites). Often this discoloration becomes extensive in a very short time. In cardiac-related deaths, the face often appears red or purple in color regardless of the positioning at or after death.	As the decedent is handled (e.g., while bathing and dressing), the nurse informs the family member about this normal change that occurs after death. Discoloration is more pronounced in the areas of the body that are dependent. Positioning the person on his or her back and not on either side is critical. Using pillows to assure the person stays on his or her back is encouraged to minimize visual discoloration. Prop the body up with pillows under the head and shoulders or raise the head of the bed at least 30 degrees. Remove heavy blankets and cover the person with a light blanket or sheet.

and desires that direct this activity—not the nurse's. The nurse's role is to facilitate and support these rituals and to assure that families have sufficient time to complete them. There are, again, no rules that govern the appropriateness of rituals; rituals are comforting and serve to begin the process of healing and acceptance.

To facilitate the grieving process, it is often helpful to create a pleasant, peaceful, and comfortable environment for family members who wish to spend time with the body, according to their desires and cultural or religious traditions. The nurse should consider engaging family members in after-death care and ritual by inviting them to either comb the hair or wash the person's hands and face, or more if they are comfortable. Parents can be encouraged to hold and cuddle their baby or child. Including siblings or other involved children in rituals, traditions, and other EOL care activities according to their developmental level is also essential. During this time, family members should be invited to talk about their family member who has died and encouraged to reminisce—valuable rituals that can help them begin to work through their grief.

The family should be encouraged to touch, hold, and kiss the person's body, as they feel comfortable. Some may wish to clip and save a lock of hair as a keepsake. The nurse may offer to dress the person's body in something other than a hospital gown or other nightclothes. Babies may be wrapped snugly in a blanket. Many families choose to dress the body in a favorite article of clothing before removal by the funeral home. It should be noted that, at times, when a body is being turned, air escapes from the lungs, producing a sighing or gasping sound. Informing family members of this possibility is wise. Again, modeling gentle and careful handling of the body can communicate care and concern on the part of the nurse and facilitate grieving and the creation of positive and long-lasting memories.

It is best to leave tubes, drains, and other devices for the funeral director to remove as special chemicals may be needed to treat the site. Mortuaries also have the facilities to dispose of any medical waste. Placing a waterproof pad, diaper, or adult incontinence brief on the patient often prevents soiling and odor as the patient's body is moved and the rectal and urinary bladder sphincters relax. Packing of the rectum and vagina is unnecessary because not allowing these areas to drain increases the rate of bacterial proliferation that naturally occurs.

Occasionally families, especially in the home care setting, wish to keep the person's body at home, perhaps to wait for another family member to come from a distance and to ensure that everyone has adequate time with the deceased. The body can, in most cases, remain in the home for approximately 12–16 hours before further decomposition and odor production occur. If the family wishes to have the body remain in the home, the nurse can suggest to the family that they adjust the temperature in the immediate area to a comfortable but cooler level and remove heavy blankets or coverings. Be sure, however, to inform the funeral director that the family has chosen to keep the body at home until a designated time. Remember, reputable funeral directors are a reliable source of information regarding postdeath changes, local customs, cultural issues, and state laws

Care of the body after death is a significantly meaningful experience for nurses. In addition to mindfully providing support for the family, including preparing the body for viewing, many nurses regard care of the body as a sacred act, communicating dignity for the person who died and his/her family. Support of co-workers and management in providing after death care is critical and enhances job satisfaction and coping with the demands of caring for persons and their families/close others at the end of life.[34]

The care of patients and families near the time of death and afterward is an important nursing function—arguably one of the most important. As the following case studies are reviewed, consider how the nurse interceded in a positive manner, mindful of the changing tempo of care and the changing patient and family needs, desires, and perspectives.

Case Study: A Patient with Parkinson's Disease and Dementia

Bill, 88 years old, was a "tough bird." He was raised in the south during the Depression, served in the Army during World War II, and had a storied career in the aerospace industry. He lived with his 90-year-old wife of 65 years. Together, they were active in their church and community and had a close network of friends. They had two married daughters and grandchildren, who "were not close by."

Bill was diagnosed with Parkinson's disease at the age of 82. As the neurological symptoms progressed, Bill, on his own volition, sold his woodworking tools, and "let go" of his woodworking hobby. Life quickly became very frustrating and "depressing."

Goals and framework of care: Bill and his wife had bought funeral plots and planned their services when they were in their early 60s. His after-death plans were clear. Suddenly, he was obsessed with how life would be until he did die. His visits to his neurologist resulted in "he says I'm doing fine. Not to worry." His wife accompanied him on the visits and heard the same thing. Both Bill and his wife were seeking more answers about what the future would hold. However, they soon recognized that there simply were no answers. Their family stepped in to encourage them to travel as much as they could and continue to participate in community activities. Gradually, these activities became more and more difficult. Bill lost his motivation to leave the house. And he became increasingly angry. Episodes of paranoia became more and more frequent. His family physician suggested an antidepressant drug. Bill refused it, saying "He's trying to kill me."

Goals and framework of care, revised: Family members developed increasing concern for the safety of Bill's wife. Home hospice was asked to visit and evaluate the situation. With great discretion, the evaluation was competed, and Bill was determined eligible for acceptance into home hospice with a diagnosis of Failure to Thrive. Home care services were put in place, with key goals of establishing a relationship of trust with Bill. Bill's wife continued to handle the majority of his care, as he refused assistance from others, including their children. During one of the daughter's visits, Bill became angry and lashed out at her. Hospice staff encouraged the wife and mother to get Bill to take an additional dose of an antipsychotic drug that was in the home, but he refused. Instead, he picked up a skillet and threatened to harm his wife. Hospice personnel supported the family in calling 911. Bill was transported to the hospital and emergently detained.

Final care revision: Bill was sedated and transferred to an inpatient hospice unit. A computed tomography (CT) scan of his head was done to rule out any underlying diseases the team was unaware of. It showed no evidence of additional disease; rather, it was simply characteristic of advanced dementia findings. A family conference was held, and the goal of care was to use medications to prevent Bill from experiencing hallucinations and paranoia. If the side effect of this approach was sedation that prevented Bill from interacting with his environment, the family was in agreement that this was the best symptom management possible. Bill died peacefully, 8 days later. His funeral proceeded, honoring his long established wishes.

Case Study: A Patient with Lymphoma

Jane, 66 years old, was diagnosed with lymphoma at the age of 51. She was successfully treated and remained disease-free for 15 years. During the 15 years of remission, her husband died suddenly of cardiac arrest. Her three sons all married, and she had become a grandmother five times. She sold her home, retired, and moved to a senior citizen apartment complex. The recurrence of the lymphoma happened shortly after her move to the apartment and presented as a bowel obstruction, requiring surgery.

Goals and framework of care: Recovery from the surgery required Jane to be transferred to a rehab facility with the goal being to build physical ability to accomplish activities of daily living (ADLs) and live independently in her apartment. Her children and grandchildren were available to assist her as needed upon her return to her apartment. She would begin chemotherapy as soon as she was discharged from the rehab center. Jane and her family were optimistic that she could respond to second-line treatment and have a good quality of life again, even though they doubted that it would be another 15 years. Jane was clear: she wanted “at least 10 more years” and would fight for that.

After 5 weeks in the rehab center, Jane returned to her apartment. She was scheduled for chemotherapy the following Monday. She and her children took the weekend to make a short day trip to visit family and her husband’s grave. She was able to have a serious conversation about her wishes. And it was clearly, “I’m going to fight this.”

Goals and framework of care, revised: During her weekend trip, Jane developed abdominal pain and vomiting. On the way home, the family brought Jane to the emergency room where the staff confirmed Jane’s fears: the bowel obstruction had recurred. She was admitted, and although the obstruction did not require surgery, the decision to start chemotherapy was placed on hold. Instead, it was decided to try radiation of the area. After 3 days, she was transferred to an assisted living facility. As the pain from the obstruction was controlled, Jane once again told staff, “I’m ready to fight.” Jane and her family were offered a family conference, but refused. “I have no questions” was her response.

At the end of a week, Jane’s abdominal pain increased in intensity. Jane was rehospitalized for pain control. The attending physician “ordered” a family conference. Jane allowed nursing staff and social services to contact her three sons and facilitate the meeting.

Final care revision: A 90-minute family meeting took place with Jane, her three children, and four adult grandchildren in attendance. After a lengthy discussion, the physician explained how he was recommending pain control be achieved and that this was best done with hospice staff members skilled in pain management. Jane and her family asked for time to talk about this. The physician said he would be available for them the next morning. Later that evening, Jane asked the nurse caring for her to contact the physician if he was available. It happened that the physician was still in the hospital. He returned to Jane’s bedside, and Jane requested that she be admitted to a hospice program.

Jane was transferred to an inpatient hospice 24 hours later. She died peacefully, 72 hours later.

Conclusion

Assisting and walking alongside dying patients and their families, especially near and after death, is an honor and privilege. Nowhere else in the practice of nursing are our words, actions, and guidance more important. Caring for dying patients and their families is indeed the essence of nursing. Take this responsibility seriously, understanding that although it may be stressful and difficult at times, it comes with personal and professional satisfaction beyond measure. Your patients and families are the guides to this remarkable and momentous journey.

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CHAPTER 34

Spiritual Screening, History, and Assessment

Elizabeth Johnston Taylor

Key Points

- A tiered approach to assessing a patient's spirituality often expects that the nurse or other trained volunteer or clinician first conducts an initial screening for spiritual problems or needs. Salient spiritual screening questions include: "How does your spirituality help you to live with your illness?" and "What can I/we do to support your spiritual beliefs and practices?"
- Numerous typologies identifying the dimensions of spirituality exist and provide guidance for what to address in a spiritual history or assessment.
- Spiritual history and assessment strategies include obtaining spiritual timelines, life stories, and pictorial depictions of spiritual experience, as well as asking simple questions.
- Although spirituality should be assessed near the time of admission to palliative care service, the process of assessment should be ongoing.
- Spiritual assessment data should be documented to at least some extent.

Spiritual Screening, History, and Assessment

To solve any problem, one must first assess what the problem is. Consequently, the nursing process dictates that the nurse begin care with an assessment of the patient's health needs. Although palliative nurses are accustomed to assessing patients' pain experiences, hydration status, and so forth, they less frequently participate in assessing patients' and family members' spirituality.

Because spirituality is an inherent and often extremely valued dimension for those who receive palliative nursing care, it is essential that palliative care nurses know how to assess spirituality. This chapter reviews models for spiritual screening, history-taking, and assessment; it also offers general guidelines on how to conduct these three tiers for assessing patient spirituality and discusses what the nurse ought to do with the obtained data. These topics are prefaced by arguments supporting the need for spiritual assessments and descriptions of what spirituality "looks like" among the terminally ill.

What Is Spirituality?

Numerous analyses of the concept of spirituality have identified key aspects of this ethereal and intangible phenomenon. Nursing conceptualizations of spirituality often include the following as aspects of spirituality: the need for purpose and meaning, forgiveness, love and relatedness, hope, creativity, and religious faith and its expression.[1] For example, Weathers, McCarthy, and Coffey recently concluded from a concept analysis of "what is spirituality" that it "is a way of being in the world in which a person feels a sense of connectedness to self, others, and/or a higher power or nature; a sense of meaning in life; and transcendence beyond self, everyday living, and suffering."[2(p. 93)]

Usually, spirituality is differentiated from religion—the organized, codified, and often institutionalized beliefs and practices that express one's spirituality.[3] To use a dated but nevertheless helpful metaphor: "Spirituality is more of a journey and religion may be the transport to help us in our journey."[4(p. 141)] Definitions of spirituality typically include transcendence—that is, spirituality explains persons' need to transcend the self, often manifested in recognition of an Ultimate Other, Sacred Source, Higher Power, Divinity, or God. Although these definitions allow for an open interpretation of what a person considers to be sacred or transcendent, they may be inappropriate for atheists, humanists, and those who do not accept a spiritual reality.

Indeed, a pluralistic definition of spirituality (however "elastic" and vague it is) is necessary for ethical practice, and hence a spiritual screening and history-taking process that is sensitive to a myriad of worldviews is essential—it is even appropriate for those who reject a spiritual reality.[5] The assessment methods introduced in this chapter are all influenced inherently by some conceptualization of spirituality. It is important to note, therefore, that the literature and methods for spiritual assessment presented in this chapter are from the United States and Europe, influenced most by Western Judeo-Christian traditions and peoples. Hence, they are most applicable to these people.

Why Is It Important for a Palliative Care Nurse to Assess Spirituality?

Spiritual awareness increases as one faces an imminent death.[6] Although some may experience spiritual distress, others may have a spiritual transformation or experience spiritual growth and health. For example, in a sample of persons with cancer, nearly one-quarter reported spiritual distress.[7,8] In a sample of 292 consecutive cancer patients receiving palliative care, however, 44% were identified as having spiritual pain—that is, "pain deep in your soul (being) that is not physical."[9] The average amount of spiritual pain among these patients was 4 (0 = best, 10 = worst). When assessing the prevalence of spiritual "needs" among New Yorkers receiving outpatient palliative care ($N = 727$), 79% reported at least one[10]; among 285 German cancer patients, 94% identified at least one need at least *a little*; the average number of needs was 8.6 (range = 0–19).[11] These observed variations in the frequency of spiritual distress or pain may be related to the variation in how the phenomenon was studied and among whom it was studied.

There is also mounting empirical evidence to indicate that spirituality moderates health-related quality of life (QOL) among persons with terminal illnesses.[12] Whether the terminally ill are persons with cancer, end-stage renal disease, or heart failure, there is evidence that spiritual well-being is also associated with coping and psychological adaptation.[13–16] Family caregivers of seriously ill patients also find comfort and strength from their spirituality that assists them in coping.[17,18] Religious beliefs and practices (e.g., prayer, beliefs that explain suffering or death) are also known to be valued and frequently used as helpful coping strategies among those who suffer and die from physical illness.[3] Indeed, it may be that spiritual distress and transformation occur concurrently; the distress may prompt the transformation.

Evidence from research suggests that attention to the spirituality of terminally ill patients and their caregivers is of utmost importance.[19] That is, if patients' spiritual resources assist them in coping, and if imminent death precipitates heightened spiritual awareness and concerns, and if patients view their spiritual health as most important to their QOL, then a spiritual assessment that initiates a process promoting spiritual well-being is vital to effective palliative care.

It is for reasons such as these that several organizations offer mandates for assessing and addressing spirituality among persons receiving palliative care. The National Consensus Project (NCP) and National Quality Forum included guidelines and preferred practices for supporting spirituality in palliative care.[20] The NCP guidelines (5.1) state: "Spiritual and existential dimensions are assessed and responded to based upon the best available evidence, which is skillfully and systematically applied." Similarly, the Hospice and Palliative Nurses Association's position paper on spiritual care affirms that spiritual care is "essential" to palliative care, and that this care "requires" assessment.[21] Likewise, The Joint Commission (TJC) stipulates that comfort and dignity be a priority for patients receiving end-of-life care in an approved facility, and that this includes spiritual care as well as other types of care[22]; although the TJC no longer discusses spiritual assessment specifically, it is assumed that assessment must precede such care. These mandates presumably cascade from the World Health Organization's definition of *palliative care* as holistic, including "early identification and impeccable assessment and treatment of spiritual [problems]."[23]

Why should palliative care nurses be involved in assessing patient spirituality? After all, chaplains and clergy are the spiritual care experts. Although chaplains are the trained experts in spiritual care, current thinking on this topic espouses that all members of a hospice team participate in spiritual caregiving. Indeed, findings from several studies suggest that this team approach to spiritual care is beneficial.[19] This position was advocated during a multidisciplinary consensus project that offered the following guidelines for spiritual care at the end of life:

- All patients should be screened for spiritual distress upon admission and a referral made if support is needed.
- Structured assessment tools are recommended to aid documentation and evaluation of care.
- All palliative care clinicians should be trained to recognize and report spiritual distress.
- All clinicians should be trained to perform a spiritual screening; more thorough assessments are to be completed by a certified chaplain.
- Screenings, histories, and assessments should be documented.
- Patients should be reassessed when there is a change in their condition.[24]

Not only do professional palliative care recommendations include nurses in the process of spiritual assessment, but also generic nursing ethics and professional standards support the nursing role in health-related spiritual and religious screening and history-taking.[3] Indeed, considering nurses' frontline position, coordination role, and intimacy with the concerns of patients; the holistic perspective on care; and their lack of association with a particular religion, nurses can be the ideal professionals for completing an initial spiritual screening or history-taking if they have some preparation for doing so.

However, nurses must recognize that they are not specialists in spiritual assessment and caregiving; they are generalists.[25] Most oncology and hospice nurses perceive that they do not receive adequate training in spiritual assessment and care. In fact, it is this lack of training, accompanied by role confusion, lack of time, and other factors that nurses often cite as barriers to completing spiritual assessments.[26,27] Therefore, when a nurse's screening or history indicates need for further sensitive assessment and specialized care, it is imperative that a referral to a spiritual care specialist (e.g., chaplain, clergy, patient's spiritual director) be made.

How Does Spirituality Manifest?

To understand how to assess spirituality, the palliative care nurse must know what to look for. What subjective and objective observations would indicate spiritual distress or well-being? Numerous descriptive studies have identified the spiritual needs of patients and their loved ones facing the end of life.[28] Whereas any listing of what spiritual issues might arise at the end of life would be incomplete, Puchalski and colleagues[24] provided a fairly comprehensive listing; these are illustrated in Table 34.1.

Although the terminology "spiritual need" may suggest a problem, spiritual needs can also be of a positive nature, as the final bullet in Table 34.1 illustrates. For example, patients can have a need to express their joy about sensing closeness to others or have a need to pursue activities that allow expression of creative impulses (e.g., artwork, music-making, writing). The following models for assessing spirituality will provide further understanding of how spirituality manifests.

Models for Assessing Spirituality

Healthcare professionals from multiple disciplines offer models for assessing spirituality. The most useful models from chaplaincy, medicine, social work, and nursing will be presented here. Although some assessment models have been published recently, many were developed since the 1990s, when the research about spiritual care began to proliferate. Although some were developed

Table 34.1 Spiritual issues at the end of life

Spiritual issues at the end of life	Examples
Lack of meaning and purpose	"Why do I have to suffer on the way to death? Why couldn't I just go to my death in my sleep?" (meaninglessness of suffering) "I feel like I never really did anything important in life, and now it's too late." (purposelessness)
Despair and hopelessness	"I just want to give up; it is not worth it anymore." (despair) Suicidal ideation (hopelessness)
Religious struggle	"Sometimes it is hard to believe there is a loving God upstairs that has my best interests in mind." "I used to believe. . . , but now how could It?"
Not being remembered	"Death is just so final; I know my friends will eventually move on and I'll have been like a blip on the monitor."
Guilt or shame	"I think my cancer is a punishment for something I did when I was young." (guilt) "I'm mortified that I'd get cancer in my private area." (shame)
Loss of dignity	"Look and smell this body! It's so embarrassing . . . it's not me anymore." "I'm such a burden now."
Lack of love, loneliness	"Everyone is so busy. . . . too busy to take care of me."
Anger at God/others	"Why would a loving God allow this to happen to me?" "Why did that corporation pollute the water where we lived for so long?"
Perceiving abandonment by God/others	"I feel like my prayers aren't being answered . . . where is God?" "The folks from church have stopped coming to visit; I guess I've been sick too long and they are tired of me."
Feeling out of control	"I'm ready to go . . . but it's not happening."
Need for reconciliation	Desire to be reunited with estranged family members
Grief from losses	Spiritual issues often accompany the various losses persons mourn when living with a terminal illness, such as the loss of independence, social roles and vocation, body image, and function.
Need for gratitude	"Now I have learned to appreciate the little things in life, and I'm just so happy for each new day that dawns." "I wish I didn't need to rely on others so much; but I am so thankful for how people do help me."

by clinicians caring for the terminally ill, others—easily adapted or used with those at the end of life—were developed for general use for those with an illness.

A two-tiered approach to spiritual assessment has been advocated.[3,29] That is, a brief assessment for screening purposes is conducted when a patient enters a healthcare institution. If the screening assessment generates an impression that there are spiritual needs and the patient desires support from healthcare team members, then spiritual care should be planned only after further information is collected. The second tier of assessment allows for focused, in-depth assessment so that patient-specific care can be delivered.

More recently, however, a three-pronged approach to assessing patient spirituality is accepted.[19,24] That is, the process of assessment of spirituality can potentially include:

- Spiritual screening
- Spiritual history-taking
- Spiritual assessment

These three approaches, as well as when they are appropriate, will be described next.

Spiritual Screening

One purpose of a spiritual screening is to determine if the patient presents with any spiritual distress and if they wish for the healthcare specialist or team to provide spiritual support. This screening can be conducted by anyone who has received training to do so.[7,24] Thus, a screening should involve only one or very few questions.

Several stand-alone screening questions have been developed and/or evaluated during research. These include:

- "Are you at peace?" This question was found to correlate highly with spiritual and emotional well-being in a large study of terminally ill patients.[30]
- "How important is spirituality or religion to you?" Research findings from 114 terminally ill persons found this single question about the importance of religion to be more discriminating than a question about frequency of attendance at religious services.[31]
- "[How much do you have] pain deep in your soul (being) that is not physical?" Fashioned after the Edmonton Symptom Distress Scale, this item is accompanied by response options from 0 (best) to 10 (worst) spiritual pain.[9]
- A global "overall spiritual well-being" item with response options on a 7-point scale from 1 (very poor) to 7 (excellent), as well as a don't know/can't answer option, was developed by the European Organization for Research and Treatment of Cancer (EORTC) for use in research and clinical practice.[32]
- "What is really important to you?" This is a spiritual screening item used by Fletcher in an Australian community-based palliative care service.[33] Designed for use within a multidisciplinary team, this item is the initial question of the Connecto model which aims to understand a patient's connections/disconnections

within/between self, others, creation, and mystery or that which is transcendent. Thus, the model guides clinicians to listen to the patient's response and indicate on a diagram how the "the self" is connected to:

- self (e.g., whether the patient is accepting, self-forgiving, possessing inner peace and self-knowledge, versus despairing, fearful, and suppressing feelings);
- others (e.g., sensing belonging and being valued, versus alienation, withdrawal, conflict);
- creation (e.g., appreciating, wondering, versus global loneliness, missing nature)
- Something Bigger (e.g., hope, meaning, awe, sacredness, versus doubt, inability to transcend the present); and
- religiosity (e.g., connection to a faith community versus loss of that connection or "backslidden").

These screening questions assess simply how important spirituality is to the patient or how much spiritual distress or well-being they experience. These questions do not determine the preferences of the patient with regard to receiving spiritual support, if spiritual needs exist. The following screening protocols, however, do.

- ◆ Physicians Lo and colleagues[34] proposed the following questions for use in palliative care settings: (a) Is faith/religion/spirituality important to you in this illness? Has faith been important to you at other times in your life? (b) Do you have someone to talk to about religious matters? Would you like to explore religious matters with someone?
- ◆ Chaplain Fitchett's research team has evaluated the Rush Spiritual Screening Protocol, what may be the most widely recognized approach.[7] It first asks patients how important spirituality or religiosity (S/R) is to them. Then, based on their response, the clinician follows up with (a) whether the patient perceives their spiritual support is adequate (for those who indicate S/R is important to some degree) or (b) whether the patient has previously found S/R supportive (for those who indicate S/R is not presently important). For those who indicate a deficiency in spiritual support or who indicate that S/R was previously important (and a life experience like the present illness triggered a change), the patient is referred to a chaplain. For a study to evaluate the accuracy of several one-item spiritual screening questions, Fitchett and colleagues rephrased this protocol as follows: "Does your religion/spirituality provide you all the comfort and strength you need from it right now?" Answer options included not applicable, and four options between not at all and a great deal.
- ◆ One tick box on the National Comprehensive Cancer Network's Distress Thermometer list of problems is "spiritual/religious concerns." The thermometer indicates responses can range from no distress to extreme distress.[35]

Although other screening questions have been offered by clinician scholars,[36] the preceding may be the most suited for inclusion in written intake assessment forms that patients complete upon admission to palliative care, given their quantitative or tick box response options. King and colleagues investigated the sensitivity of six spiritual screening questions (several of which are identified in the preceding list) and found none of them reached the desired 85% sensitivity they a priori determined was necessary.[37] Indeed, they observed the frequency of reported spiritual struggle ranged from 13% to 38% in this sample of 1,449 cancer survivors, depending on screening question. After additional analysis, they concluded that the most sensitive approach to screening should include the following two items: "Do you struggle with the loss of meaning and joy in your life?" and "Do you currently have what you would describe as spiritual or religious struggles?"

The spiritual screening questions can determine (with some, but not complete, accuracy) how important S/R is to a patient or family caregiver, whether there is spiritual distress, and/or whether they would appreciate support. A caveat is in order, however, regarding the role of non-chaplain clinicians inquiring whether spiritual support is desired. Some chaplains may not want clinicians to inquire if patients want a chaplain visit. They fear that if the nurse does it and receives a negative response, then they do not have permission to approach the patient. Indeed, there is evidence from a Swiss study that when a hospital chaplain asked a patient if spiritual support was desired, 86% agree; however, when nurses asked using a scripted question (i.e., "Do you want to have the visit of the chaplain of this hospital unit?"), only 37.5% agreed to have a chaplain visit.[38] Although this is only one study, it points to the importance of collaborating with chaplains in selecting a screening protocol.

Spiritual History-Taking

A spiritual history is also to be taken at the beginning of any relationship with palliative care; the reason is to obtain more details about the patient's spirituality and religiosity so that any care (physical, emotional, or spiritual) can be provided with sensitivity to this fundamental dimension. An expert panel recommended that the spiritual history be obtained by the primary care provider. In palliative care, it is typically the patient's primary nurse who is responsible for coordinating care and should complete this level of assessment.[24]

Several clinicians have devised models for use in spiritual history-taking. Several of these include apropos mnemonics. The most widely cited tool is Puchalski's Faith, Import, Community, Address (FICA) tool, which has been validated as feasible within a hospital palliative care service and among nursing students.[39,40] Whereas Maugens's[42] and Vermandere et al.'s[45,46] models were specifically designed for use in palliative care, the rest were generically designed but can be used just as well in palliative care.

The history-taking models in Table 34.2 are dependent on the clinician's verbally interviewing the patient. It is possible, however, that the initial screening and history-taking process can be accomplished using a standardized paper-and pencil questionnaire. There are dozens of instruments developed for measuring aspects of spirituality and/or religiosity for research purposes. Instruments for collecting clinically relevant data without undue burden, however, are few.

Table 34.3 presents questionnaires that are most likely to hold promise for palliative care patient spiritual history-taking. These questionnaires were selected for their brevity, validity, and/or clinical relevance. Whereas the SNAP[49] and HEALS[50] were created specifically for palliative care patient assessment and reflection, the others were designed for the generic patient or person.

This approach to spiritual assessment allows for identification and, possibly, measurement of how one spiritually believes, belongs, and behaves. In other words, using an instrument for

Table 34.2 Spiritual history models

Author/s	Components (mnemonic)	Illustrative questions
Anandarajah and Hight[41] HOPE model	H (sources of hope)	What or who is it that gives you hope?
	O (organized religion)	Are you a part of an organized faith group? What does this group do for you as a person?
	P (personal spirituality or spiritual practices)	What personal spiritual practices, like prayer or meditation, help you?
	E (effects on medical care and/or end-of-life issues)	Do you have any beliefs that may affect how the healthcare team cares for you?
Maugens[42] SPIRIT model	S (spiritual belief system)	What is your formal religious affiliation?
	P (personal spirituality)	Describe the beliefs and practices of your religion or spiritual system that you personally accept. What is the importance of your spirituality/religion in daily life?
	I (integration with a spiritual community)	Do you belong to any spiritual or religious group or community? What importance does this group have to you? Does or could this group provide help in dealing with health issues?
	R (ritualized practices and restrictions)	Are there specific elements of medical care that you forbid on the basis of religious/spiritual grounds?
	I (implications for medical care)	What aspects of your religion/spirituality would you like me to keep in mind as I care for you? Are there any barriers to our relationship based on religious or spiritual issues?
	T (terminal events planning)	As we plan for your care near the end of life, how does your faith impact on your decisions?
McEvoy's BELIEF model (for use in pediatric care)[43]	B (belief system)	What religious or spiritual beliefs, if any, do members of your family have?
	E (ethics or values)	What standards/values/rules for life does your family think important?
	L (lifestyle)	What spiritual habits or activities does your family commit to because of spiritual beliefs (e.g., any sacred times to observe or diet you keep)?
	I (involvement in spiritual community)	How connected to a faith community are you? Would you like us to help you reconnect with this group now?
	E (education)	Are you receiving any form of religious education? How can we help you keep up with it?
	F (near future events of spiritual significance for which to prepare the child)	Are there any upcoming religious ceremonies that you are getting ready for?
Puchalski[44] FICA model	F (faith)	Do you have a faith belief? What is it that gives your life meaning?
	I (import or Influence)	What importance does your faith have in your life? How does your faith belief influence your life?
	C (community)	Are you a member of a faith community? How does this support you?
	A (address)	How would you like for me to integrate or address these issues in your care?
Vermandere, et al.[45,46] "Ars Moriendi" model	Holding on vs letting go	What gives you strength in this situation? Who/what inspires you? Whom are you holding on to? Can you let go of life?
	Joyous vs forgetting	If you look back upon your life, what do you feel? Are there important things to discuss with anyone still?
	Knowing vs believing	What does death mean to you? Do you feel supported by any beliefs or faith?
	Oneself vs The Other	Are you leaving the world in the way that you want? Are you able to be yourself? Feel authentic?
	Doing vs underdoing	How are you holding up? Is there any way we can support you?

assessment purposes allows for the measurement of spirituality. This standardized measurement can allow comparison between time points in a patient's illness experience and between patients, to determine what may be "normal" or unusual. Caution in this regard, however, is urged.

When using a quantitative instrument for obtaining spiritual information from a patient, it is important to recognize the limitations of such a method. First, this type of tool should not "stand alone" in the process of spiritual assessment; rather, it can be the springboard for a more thorough assessment and deeper encounter with a patient, as appropriate. A quantitative tool should never replace human contact; rather, it should facilitate it. Second, there are potential negative implications of comparing how a patient "measures up" with others. Noting to what degree a patient is spiritually struggling or is intrinsically religious should not bring with it an evaluative judgment. Third, collecting spiritual distress or well-being information with a questionnaire can delude clinicians into thinking "that box is ticked." Instead, any written assessment process must be accompanied by face-to-face interaction that allows the patient to debrief about the process;

Table 34.3 Spiritual history-taking instruments

Instrument name	Instrument description	Illustrative items
Functional Assessment of Chronic Illness Therapy-Spiritual Well-being (FACIT-Sp)[47,48]	12-item instrument with 5-point response options ranging from "not at all" to "very much." Assesses both religious and existential/spiritual well-being (or faith and meaning, and possibly peace). Strong psychometric support; widely used for health-related research purposes.	"I feel peaceful." "I am able to reach down deep into myself for comfort."
Spiritual Needs Assessment for Patients (SNAP)[49]	Systematically developed and tested, and found to have good support for its validity and reliability. Measures psychosocial domain (5 items), spirituality (13 items), and religious needs (5 items). Response options range from 1, "not at all," to 4, "very much."	Resolving old disputes, hurts or resentments among family and friends Religious rituals such as chant, prayer, lighting candles or incense, anointing, or communion
Healing Experience in All Life Stressors (HEALS)[50]	48 items with response options from strongly disagree (1) to strongly agree (5). Tested in small sample, yet obtained internal consistency (Cronbach's alpha) of 0.94. Factor analysis indicated 5 subscales: religion, family, meanings placed on interaction with the world, intrapersonal, and psychological growth.	"My religious beliefs give me hope." "I have greater appreciation for my life." "I accept things that I cannot change." "I feel isolated."
Spiritual Needs Questionnaire[51]	19-item scale with 4-point responses measuring degree of agreement/disagreement. Developed in Germany, so wording may not be fitting for North American patients. Tested with cancer and chronically ill patients with pain. Cronbach's alpha observed was 0.93; factors analysis identified 4 subscales measuring religious needs (6 items), need for inner peace (5 items), existential/meaning (5 items), and actively given of oneself (3 items).	Read religious/spiritual books Dwell at a place of quietness and peace Talk to someone about the meaning of life Give away something from yourself
Daily Spiritual Experience (DSE)[52]	16-item scale with Likert-type response options measuring frequency of perception of the transcendent (e.g., God) in daily life. Developed and tested in culturally and religiously diverse samples. Has been used often in research; well-established validity.	"I am spiritually touched by the beauty of creation." "I feel a selfless caring for others." "I accept others even when they do things I think are wrong."
Duke Religion Index (DUREL)[53]	5-items that measure 3 concepts: organizational religiosity (1 item); non-organizational religiosity (1 item); and intrinsic religiosity (3 items). Only IR items can be summed, as other items measure different concepts. Frequently used in research; psychometrically well supported.	How often do you attend church or other religious meetings? [organizational religiosity] How often do you spend time in private religious activities, such as prayer, meditation, or Bible study? [nonorganizational religiosity] "My religious beliefs are what really lie behind my whole approach to life." [1 of 3 intrinsic religiosity items]
Spiritual/Religious Struggles Scale[54]	The RSSS includes six subscales (in 26 items) with 5-point response options that can be used alone or in concert. The six subscales measure supernatural (i.e., divine and demonic), interpersonal, and intrapersonal (moral, ultimate meaning, doubt) struggles. The RSSS was rigorously developed and evaluated.	"Questioned whether my life will really make any difference in the world." "Felt troubled by doubts or questions about religion or spirituality." "Felt as though God had abandoned me."
Attitudes Towards God Scale (ATGS-9)[55]	9-item scale with 4 items addressing anger and doubt, and 5 items measuring positive regard for God. Extensively tested among well persons.	To what extent do you currently: View God as unkind Feel loved by God
Spiritual Needs Inventory (SNI)[56,57]	17-items with Likert response options rating frequency in one column and whether the need was being met in another column. Items are introduced with: "In order to live your life fully, you need. . . ?" Measures 5 factors: religious needs, outlook needs, community needs, inspiration, and spiritual activities. Developed based on data from hospice patients; also validated among caregivers of hospice patients. Cronbach's alpha = 0.85.	Think happy thoughts Be with friends See smiles Be with family/friends Pray

this will also allow the clinician to gain the requisite rapport for further spiritual care.

Table 34.3 is not exhaustive. Consult existing systematic reviews of other instruments measuring spiritual needs or spiritual well-being for additional options. Consider the reviews provided by Monod and colleagues[58]; Lunder, Fulan, and Simonic[59]; and Seddigh.[60] Monod and colleagues observed that only 2 of the 35 scales measuring spirituality could have clinical usefulness. If spirituality is indeed a vital sign, as Lunder and colleagues posited, then careful consideration of how this vital essence of personhood can be screened and assessed by nurses is imperative.

Spiritual Assessment

If the screening or subsequent observation provides evidence that a spiritual need exists that might benefit from specialist-provided spiritual care, the nurse ought to make a referral to the chaplain or designated palliative care team member with expertise in spiritual care. It is the board-certified chaplain or specialist in spiritual care who then completes a spiritual assessment. The spiritual assessment is an in-depth exploration and evaluation of the patient's spiritual perspectives, concerns, and resources. A spiritual assessment is a grand tour assessment that covers multiple aspects of the patient's spirituality.[24]

Often, however, the palliative care patient or family member who has a warm and respectful relationship with their nurse will raise a spiritual/religious topic when only the nurse is available. Or they may not overtly raise the topic, yet give nonverbal or indirect evidence that there is a spiritual need. At such times, the nurse may need to complete a spiritual assessment to some degree.

When should clinicians assess spirituality further, probe more deeply? Hodge[29] suggested four criteria for determining whether to move on to a more comprehensive assessment:

- First, consider patient autonomy. The patient must give informed consent. A comprehensive assessment may drill into inner depths the patient does not wish to expose to a clinician.
- Second, consider the competency of the clinician with regard to discussing spiritual matters. Is the clinician culturally sensitive and aware of how a personal worldview might conflict with the patient's? Might the clinician suffer from religious countertransference and inappropriately relate to the patient from personal biases?
- Third, consider if the spiritual issue identified is relevant to the present healthcare situation. If not, it may not be in nurses' purview. For patients at the end of life, however, many past and diverse spiritual struggles can resurface; although these struggles may seem tangential to present caregiving, the patients may benefit from spiritual expertise that aids them in addressing these issues before death. (The nurse's curiosity or desire to evangelize the patient is never an ethical rationale for spiritual assessment.[3])
- Finally, consider the importance of spirituality to the patient. The extreme illustration of this would be if a patient states spirituality is personally irrelevant; then a comprehensive spiritual assessment would be inappropriate.

Observing these guidelines can prevent inappropriate and time-consuming assessment and care.

Although a comprehensive spiritual assessment may well be beneficial to many patients at the end of life, it is likely that few palliative care nurses are competent or able to conduct such an assessment. Fowler posited that a person's spiritual or religious experience is arranged in layers like an onion. The outer layers of public and semi-public spiritual belief and practice are an appropriate domain for the nurse negligibly trained in spiritual assessment and care, whereas the deeper, more intimate—and often pain-filled—inner layers are best assessed and addressed by spiritual care experts.[61]

With these cautionary caveats in mind, a few models for spiritual assessment are presented. These were developed by chaplains for chaplain use. They are extensive in their scope. By reviewing them, however, the nurse can increase his or her awareness of spiritual dimension and how to query and listen for them.

Possibly the first comprehensive spiritual assessment model was that developed by Pruyser,[62] the patriarch of modern chaplaincy. Pruyser's original model identified seven aspects; each of which may be viewed as a continuum. These aspects of spirituality included:

- Awareness of the holy or the lack thereof
- Sense of providence or the lack thereof
- Faith or the lack thereof
- A sense of grace or gratefulness, in contrast with a lack of appreciation and a sense of entitlement
- Repentance versus unrepentant stance toward others and the world
- Communion (or feeling part of a whole) or on the continuum toward sensing no connection with others or the world
- Sense of vocation (purpose) versus meaninglessness

Although this model is clearly influenced by a Christian worldview and may therefore be limited in its applicability, it offers a beautiful approach to thinking about spirituality comprehensively.

Fitchett,[63] a chaplain, developed the "7-by-7" model for spiritual assessment with a multidisciplinary group of health professionals. In addition to reviewing seven dimensions of a person (medical, psychological, psychosocial, family system, ethnic and cultural, societal issues, and spiritual dimensions), Fitchett advances seven spiritual dimensions to include in an assessment:

- Beliefs and meaning (i.e., mission, purpose, religious and nonreligious meaning in life)
- Vocation and consequences (what persons believe they should do, what their calling is)
- Experience (of the divine or demonic) and emotion (the tone emerging from one's spiritual experience)
- Courage and growth (the ability to encounter doubt and inner change)
- Ritual and practice (activities that make life meaningful)
- Community (involvement in any formal or informal community that shares spiritual beliefs and practices)
- Authority and guidance (exploring where or with whom one places trusts, seeks guidance)

This model likely offers chaplains and spiritual care experts the most comprehensive of all approaches to assessment.

LaRocca-Pitts[64] offered the FACT spiritual assessment model for chaplains. This model explores the following aspects of a patient's spirituality and religiosity: facts (or the patient's current situation), feelings, family and friends, faith, fun, finances, function (or role in society, family), fame/fortune (or impact on the world), future understanding (what they perceive is in their future). For each of these "F" aspects of life, the chaplain can assess its "A" (access or availability, or related anxiety), "C" (coping, or conflict or comfort related to it), and "T" (treatment, or an evaluation of treatment outcomes). This model may be broader in scope than others (e.g., includes examining how finances impact their spiritual state) yet can still be helpful to those in palliative care.

Shields's[65] Spiritual Assessment and Intervention Model (AIM) does not provide a catchy mnemonic, but instead a detailed philosophic and empirically derived description of how a chaplain can approach spiritual assessment and intervention. Spiritual AIM is based on three fundamental assumptions. First, it accepts the psychological theory (and subsequent supportive empirical evidence) of object relations; that is, it is within relationships that humans develop spiritually. It is our initial relationships that most influence how we view the divine and interpret spiritual experiences. For example, how a believer experiences his or her biological father influences how he or she views God. Thus, spiritual healing requires examining how and why a patient relates to others.

Second, Shields's[65] Spiritual AIM accepts and bases clinician–patient interaction on the ethic of reciprocity. That is, love of self is a concurrent experience with love of others and the divine (e.g., the Golden Rule). Third, Spiritual AIM accepts that there are three core spiritual needs among humans. These include the need (1) for meaning and direction, (2) for self-worth and belonging within a community, and (3) to love and be loved (e.g., be reconciled to those from whom one is estranged). Shields observed that when a person is in crisis, at least one of these spiritual needs manifests.

Other Spiritual Assessment Methods

Other approaches to spiritual assessment have been described in addition to the interview and questionnaire techniques. Life reviews can become, in essence, spiritual assessments. Life reviews are especially valuable for persons who are dying as they allow patients to make sense of and reconcile their life story. By doing a life review with a terminally ill patient, the nurse can assess many dimensions of spirituality (e.g., worldviews, commitments, missions, values) in a natural, noncontrived manner. Life reviews can be prompted by questions about the significant events, people, and challenges during the life span. A life review can also occur when inquiring about personal objects, pictures, or other memorabilia the patient wants to share. A meta-analysis of eight studies of the effectiveness of life reviews concluded that it improves QOL among terminally ill.[66]

Chochinov and various colleagues around the world have developed and tested *dignity therapy*, which basically allows persons at the end of life an opportunity to do a life review.[67] The semi-structured questions of dignity therapy include the following: "Tell me a little about your life history, particularly the parts you either remember most or think are most important? When did you feel most alive? Are there specific things that you would want your family to know about you? What are the most important roles you have played in life? What are your most important accomplishments? Are there particular things that you feel still need to be said? What are your hopes and dreams for your loved ones? What have you learned about life that you would want to pass along? Are there other things that you would like included?" The patient's responses to these questions, potentially asked by a trained volunteer, are recorded and transcribed into a permanent record that the patient helps to design and that can be left as a legacy for loved ones. Although dignity therapy is reminiscence therapy, these questions overlap with what could be included in a comprehensive spiritual assessment.

Hodge[68] identified several creative approaches to collecting information about client spirituality. As a social worker, Hodge is well aware that some patients are not verbal or are not comfortable expressing their spirituality in words. Thus, he explained more visual ways for a patient to describe his or her spiritual experiences. These methods for assessments include:

- *Spiritual life maps*, or a pictorial depiction of where the patient has been spiritually, where the patient is presently, and where the patient expects to go. It can be a simple pencil drawing on a large piece of paper; words and illustrations can be used to convey the spiritual story—the spiritual highs and lows, blessings and burdens, and so forth.
- *Spiritual genogram*, like a standard genogram, depicts the issues and influences over one to three generations. Sources of spiritual influence from certain relationships (including those external to the family) can be drawn. Words that identify key spiritual beliefs and practices that were transmitted via relationships and significant spiritual events that contribute to the patient's spiritual life can be noted around this spiritual family tree.
- *Spiritual ecomaps*, rather than focusing on past spiritual influences, direct the patient to consider present spiritual experiences. In particular, the patient can diagram (with self portrayed in the center) the relationship with God or transcendent other/value, rituals, faith community, and encounters with other spiritual entities.
- *Spiritual ecograms* allow the patient to diagram present perspectives on both family and spiritual relationships; it is a fusion of the spiritual genogram and ecomap.

Other strategies include having clients draw a spiritual timeline that includes significant books, experiences, events, and the like. Another unusual approach involves sentence completion. For example, a client may fill in the blank of sentences like "My relation to God . . ." or "What I would really like to be . . . ," or "When I feel overwhelmed. . . ." Having verbally oriented assessment strategies as well as these nonverbal methods provides clinicians with a "toolbox" for assessing spirituality, allowing the clinician to choose an approach that fits the patient's personality, circumstances, and purpose for assessment.[68]

Summary of Spiritual Screening, History-Taking, and Assessment Models

The preceding summaries of various models for spiritual assessment identify spiritual dimensions that may be included in a spiritual assessment. Many of the dimensions identified in one model are observed (often using different language) in other models. Except for Hodge's[68] diagrammatic methods, these assessment approaches generally require the professional to make observations while asking questions and listening for the patient's response. The vast majority of questions recommended for use in following such a model are open-ended. Several of the questions—indeed, the dimensions of spirituality—identified in this literature use "God language" or assume a patient will have belief in some transcendent divinity. All these models are developed by professionals who are influenced predominantly by Western, Judeo-Christian ways of thinking.

General Observations and Suggestions for Conducting a Spiritual Assessment

When to Assess

The spiritual assessment consensus project advocated that spiritual screening should be done at admission and whenever there is a change in patient status.[24] Furthermore, when the spiritual screening suggests potential for spiritual distress, a trained chaplain should be called for a more complete assessment within 24 hours. However, spiritual assessment should also be an ongoing process. The nurse does not complete a spiritual assessment simply by asking some questions about religion or spirituality during an intake interview. Instead, spiritual assessment should be ongoing throughout the nurse–patient relationship. A nurse tuned to know how spiritual health is manifested will be able to see and hear patient spirituality as it is embedded in and suffuses the everyday encounter.

Gaining Entrée

Spiritual needs are complex and often difficult to acknowledge and, more so, to describe with words. Furthermore, the patient may not yet feel comfortable divulging such intimate information to a nurse with whom rapport has not been established. Indeed, some patients may not want to share such inner, heart-touching experiences. Evidence indicates that the requisites patients want in clinicians who provide spiritual care are relational (e.g., "show me kindness and respect" and "get to know me first"); training in spiritual care or sharing similar beliefs as the patient is less important.[69]

Because spirituality and religiosity are sensitive and personal topics (as are most other topics nurses assess), it is polite for a nurse to preface a spiritual assessment with an acknowledgment of the sensitivity of the questions and an explanation for why such an assessment is necessary. For example, Maugens suggested this preface: "Many people have strong spiritual or religious beliefs that shape their lives, including their health and experiences with illness. If you are comfortable talking about this topic, would you please share any of your beliefs and practices that you might want me to know as your [nurse]?"[42(p. 12)] Such a preface undoubtedly will help both the patient and the clinician to feel at ease during the assessment.

Assessing Nonverbal Indicators of Spirituality

Although this discussion of spiritual assessment has thus far focused on how to frame a verbal question and allow a patient to verbalize a response, the nurse must remember that most communication occurs nonverbally. Hence, the nurse must assess the nonverbal communication and the environment of the patient.[3,70] Does the patient appear agitated or angry? What does the body language convey? What is the speed and tone of voice?

Assessment of the patient's environment can provide clues about spiritual state. Are there religious objects on the bedside table? Are there religious paintings or crucifixes on the walls? Are there get well cards or books with spiritual themes? Are there indicators that the patient has many friends and family providing love and a sense of community? Are the curtains closed and the bedspread pulled over the face? Many of the factors a palliative care nurse usually assesses will provide data for a spiritual assessment as well as the psychosocial assessment.

Language: Religious or Spiritual Words?

One barrier to spiritual assessment is the nurse's fear of offending a nonreligious patient by using religious language. However, when one remembers the nonreligious nature of spirituality, this barrier disappears. Patient spirituality can be discussed without God language or reference to religion. Also, using the terms "need" or "distress" immediately after "spiritual" could be denigrating for a patient. Especially with spirituality, patients may be upset when they hear others consider them to be in need. Nurses can easily avoid such jargon.

To know what language will not be offensive during the process of assessing spirituality, the nurse must remember two guidelines.[70] First, the nurse can begin with questions that are general and unrelated to religious assumptions. For example, "What is giving you the strength to cope with your illness now?" or "What spiritual beliefs and practices are important to you as you cope with your illness?" Second, the nurse must listen for the language of the patient and use the patient's language when formulating more specific follow-up questions. If a patient responds to a question with "My faith and prayers help me," then the nurse knows "faith" and "prayer" are words that will not offend this patient. If a patient states that the "Great Spirit guides," then the sensitive nurse will not respond with, "Tell me how Jesus is your guide."

Stewart reminds clinicians of how patients use spiritual language in colloquial ways.[71] For example, how often people say things like: "Thank God!" "OMG!" "Everything happens for a reason." "God willing. . . . ," or "I'm blessed." Such spiritual expression provides a potential prompt for exploration: "OMG?" "What do you think the reason is?" or "How are you blessed?" Such exploration not only can provide clinically relevant data, but also an opportunity for the patient to reflect on their inner experience.

Questions using nonreligious language are presented in Box 34.1. These questions will allow a nurse to broach the topic of spirituality without awkwardness. They likely will emerge in the natural course of a conversation, as a patient talks about the challenges of living with illness. Such questions can allow for continued assessment without use of one of the preceding formalized protocols.

Box 34.1 Nonreligious Spirituality Questions

You've gone through so much lately. Where do you get your inner strength and courage to keep going?

What is helping you to cope?

What comforts are most satisfying for you now?

As you think about your future, what worries you most?

Some people seem more to live while they are dying, while others seem to die while they are living. Which way is it for you? What makes it that way?

What kind of person do you see yourself as? (Note: Chaplains suggest that how one views self parallels how one views one's Creator or God.)

What do you see as the purpose for your life now, given your body isn't allowing you to do all you used to do?

What hopes and dreams do you have for your future? For your family?

What legacy would you like to leave? How can we make sure that happens?

As I've gotten to know you, I've noticed you speak often of (spiritual theme [e.g., betrayal, yearning for love]). How do you think (this theme) has influenced your life, or will influence your future? How happy with your life's theme are you?

Tell me about times during your life where faced a huge challenge. What got you through? Is that resource still available to you now?

Asking Questions

Because asking a patient questions is an integral part of most spiritual assessments—and an art,[72] it is good to remember some of the basics of formulating good questions. Asking closed-ended questions that allow for short factual or yes/no responses is helpful when a nurse truly has no time or ability for further assessment. Otherwise, to appreciate the uniqueness and complexity of an individual's spirituality, the nurse must focus on asking open-ended questions. The best open-ended questions begin with "How," "What," "When," "Who," or phrases like "Tell me about. . . ." Generally, questions beginning with "Why" are not helpful; they are often mixed with a sense of threat or challenge (e.g., "Why do you believe that?").[70]

Listening to the Answers

Although it is easy to focus on and worry about what to say during an assessment, the palliative care nurse must remember the importance of listening to the patient's responses.[72] Discussion of active listening is beyond the scope of this chapter, yet a few comments are in order. Remember that silence is appropriate when listening to a patient's spiritual and sacred story; silence has a role.[70] Remain neutral, nonjudgmental. View the patient as a fellow sojourner on the journey of life. Recognize that you are not the authority or savior for the patient expressing spiritual pain. Rather you are a companion, or a supporter if so privileged. Listen for more than words. Listen for metaphors, listen for a spiritual theme that keeps re-emerging throughout life stories, listen for where the patient places energy, listen for emotion in addition to cognitions.[70,72] The nurse will do well to listen to his or her own inner response. This response will mirror the feelings of the patient.[70]

Overcoming the Time Barrier

Healthcare professionals may believe that they do not have enough time to conduct a spiritual assessment. Indeed, Maugens[42] observed that completing his spiritual history with patients took about 10–15 minutes. Although this is much less time than Maugens and his colleagues expected it to take, it is still a considerable amount of time in today's healthcare context. One response to this time barrier is to remember that spiritual assessment is a process that develops as the nurse gains the trust of a patient. The nurse can accomplish the assessment during "chit chat." Furthermore, data for a spiritual assessment can be simultaneously collected with other assessments or during interventions (e.g., while bathing or completing bedtime care). And finally, it can be argued that nurses do not have time *not* to conduct a spiritual assessment, considering the fundamental and powerful nature of spirituality.

Overcoming Personal Barriers

Nurses can encounter personal barriers to conducting a spiritual assessment. These barriers can include feelings of embarrassment or insecurity about the topic or can result from projection of unresolved and painful personal spiritual doubts or struggles. Every nurse has a personal philosophy or worldview that influences his or her spiritual beliefs. These beliefs can color or bias the nurse's assessment techniques and interpretation. Hence, an accurate and sensitive spiritual assessment presumably correlates with the degree of the nurse's spiritual self-awareness.[73] Put another way, your ability to hear your own spiritual story is directly related to your ability to hear a patient's spiritual story.[70] Nurses can increase their comfort with the topic and their awareness of their spiritual self if they ask themselves variations of the questions they anticipate asking patients. For example, "What gives my life meaning and purpose?" "How do my spiritual beliefs influence the way I relate to my own death?" "How do I love myself and forgive myself?" Recognizing how one's spiritual beliefs motivate one's vocation as a nurse is also extremely helpful.

Concluding Cautions

Although the presented models and evidence supporting spiritual screening, history-taking, and assessment imply that it is an unproblematic and simple process, it would be naïve to leave this impression. Several experts suggest potential problems associated with spiritual assessment. These include:

- The process of taking spiritual assessment data to make a spiritual diagnosis pathologizes what may be a normal process of spiritual growth. Assessment tools often assume that spiritual well-being correlates with feeling good, that spiritual health and suffering cannot coexist. A more appropriate way to evaluate spirituality may be to ask how harmful one's spirituality is to self and others.[70]
- A "tick box" approach to spiritual assessment could freeze patient spirituality to the time when the assessment was completed; spiritual assessment would be considered complete and fail to continue in an ongoing manner.[72]
- A fairly prescribed assessment tool could have the unintended outcome of disempowering a patient. That is, the clinician controls (overpowers) the agenda by determining what spiritual matters are discussed. A tool used for assessment could end up limiting and controlling patient expression.
- A spiritual assessment to some degree will reflect the assumptions influencing the clinician (a major one being that spirituality is universal). Thus, a spiritual worldview will be imposed to some degree on a vulnerable patient. An ethical spiritual assessment is nonalienating, nondiscriminating, and engages and respects the patient. Indeed, extant standardized spiritual assessment tools generally have not been tested in many cultures, so it is unknown how culturally appropriate or sensitive they are.[59]

Thus, a spiritual assessment tool—if a tool is needed—should be able to generate helpful information for guiding patient care, encourage patient participation, be flexible and easy to use, take little clinician time, be nonintrusive, allow for a patient's unique story to be understood to some degree, and be simple and clear. A tall task? Perhaps. But important to strive toward.

Assessing Special Populations

Impaired Patients

Although verbal conversation is integral to a typical spiritual assessment, some terminally ill patients may not be able to speak, hear, or understand a verbal assessment. Patients who are unable to communicate verbally may feel unheard. In such situations, the nurse again must remember alternative sources of information. The nurse can consult with the family members and observe the patient's environment and nonverbal communications. Alternative methods for "conversing" can also be used. For patients who can write, paper-and-pencil questionnaires can be very helpful. Always be patient and be unafraid of the tears that can follow. Questions that demonstrate concern for their innermost well-being may release floodgates for tears.

A creative approach developed by a chaplain for use among patients who are ventilator-dependent involves showing them cartoon pictures labeled with a word that they can indicate as reflective of their answer.[74] That is, this "picture guide" has four sections that assesses the patient's religious affiliation (with symbols for each of the major faith traditions as well as one for nonreligious perspectives), feelings (with faces depicting 24 emotions), the spiritual pain rating scale (on a 1–10 continuum), and many options for spiritual interventions that a chaplain could provide (prayer, blessing, "sit with me," and options for reading from various religious scriptures and for facilitating various religious rituals). Berning and colleagues systematically evaluated this picture guide in an intensive care unit (ICU) setting and found those who completed this assessment experienced substantial decrease in their stress.[74]

For persons with dementia or other cognitive impairments, it is helpful to recognize communication can still occur on an emotional or physical level even if positive improvements to mental state are not observed. Their disjointed stories will still offer you a window onto their world. Even if you cannot sew the pieces together, trying will help you to remain curious and engaged.[70] A meta-synthesis of eight studies describing spirituality among persons with dementia provided evidence that spirituality and religiosity often provide these persons with a reminder of their identity and comfort, given that these feel familiar. Although this synthesis of evidence did not address spiritual assessment, it does suggest that spiritual and religious practices, symbols, and rituals are important to know if we are to provide care that is comforting and respectful.[75]

Children

Several strategies can be employed to assess the spirituality of children. The clinician must remember, however, that building trust and rapport with children is essential to completing a helpful spiritual assessment. Children are especially capable of ascertaining an adult's degree of authenticity. Children also are less likely to be offended by a question about religion. If a nurse creates a comfortable and nonjudgmental atmosphere in which a child can discuss spiritual topics, then the child will talk. Never underestimate the profoundness of a child's spiritual experience, especially a dying child's.

In addition to asking assessment questions verbally, the nurse can use play interviews, picture drawings, observations, and informal interviews.[76] The nurse may need to be more creative in formulating questions if the child's vocabulary is limited. For example, instead of asking the child about helpful religious rituals, the nurse may need to ask questions about what they do to get ready to sleep or what they do on weekends. When asking, "Does your mommy pray with you before you go to sleep?" or "What do you do on Sunday or Sabbath mornings?" the nurse can learn whether prayer or religious service attendance are a part of this child's life. An assessment question that Fosarelli found to be particularly helpful with 6- to 18-year-olds was: "If you could get God to answer one question, what one question would you ask God?" [76]

While assessing children, it is vital to consider their stage of cognitive and faith development.[76,77] Questions must be framed in age-appropriate language (e.g., a 4-year-old will likely not understand what "spiritual belief" means). Toddlers and preschoolers talk about their spirituality in very concrete terms, with an egocentric manner. School-aged and adolescent children should be addressed straightforwardly about how they see their illness. Inquiring about the cause of their illness is especially important, as many children view their illness and impending death as punishment.

As with adults, nonverbal communication and behaviors are also significant forms of information for a spiritual screening or assessment. Mueller[77] advises that extensive crying, withdrawal, and regressive or resistant behaviors are potential indicators of spiritual distress. Likewise, difficulty with eating or sleeping (nightmares) and somatic complaints can be reflective of an undergirding spiritual distress.

Family Caregivers

The spiritual distress of family caregivers is not unlike that of their beloved.[17,57,78] Given the provision of 24/7 physical care, the unrelenting uncertainty and anxiety, and the constellation of stressors family caregivers endure, it is not surprising they may feel angry at God, isolated from their faith community, challenged to have a meaningful outlook on life, prone to blaming and regret, and welcoming of faith-related practices that bring meaning, comfort, and forgiveness.[17,57,79,80] Indeed, in Delgado-Guay and colleagues' study, 58% of family carers surveyed reported some spiritual pain.[78]

Parents of Pediatric Palliative Care Patients

Understanding the family's spirituality is pivotal to understanding the child's. Structured interviews or unstructured conversations with parents and even older siblings will inform the healthcare team about the child's spirituality.[76] Although it is highly unlikely that a nurse will be completing a comprehensive spiritual assessment of a family, an awareness of this process can give the nurse a richer perspective with which to conduct a screening or history when it is appropriate. Furthermore, clinician inquiry about parental spiritual needs is associated with perception of spiritual support.[81] A small study of parents of children referred to a palliative care service (76% being mothers, and 19 of the 25 interviewed being religious) found that although a third would not want a clinician to ask them about their spiritual needs, they all would not be offended or uncomfortable with a question about their spirituality or religiosity from a team member.[81] Similarly, nearly half of parents of pediatric ICU patients ($N = 162$) reported that if their child was seriously ill they would want their physician to provide spiritual care; this was especially true for the parent who self-identified as religious.[82] It is important to note, however, that this study's findings also documented that parents were twice as likely to want a chaplain's spiritual support than a physician's.

Barnes and colleagues[83] suggested the following questions as guides for assessing how a family's spirituality affects illness experience:

- How does the family understand life's purpose and meaning?
- How do they explain illness and suffering?
- How do they view the person in the context of the body, mind, soul, spirit?
- How is the specific illness of the child explained?
- What treatments are necessary for the child?
- Who is the qualified person to address these treatments for the various parts of the child's healing?

- What is the outcome measurement that the family is using to measure successful treatment (good death)?

Family Caregivers of Adults Receiving Palliative Care

Similarly, knowing the spiritual or religious family context of an adult patient can also inform clinicians about a patient's faith context. Ferrell and Baird[84] offer a couple of family spiritual assessment questions that are specific to the caregiving role many family members often perform:

- We recognize that often family caregivers' spirituality may be similar to or very different from the patient's spirituality. Are there spiritual needs you have as a family caregiver?
- Many family caregivers tell us that while caring for a loved one is very difficult, caregiving can also be a very meaningful experience. What has it been like for you?[84(p. 257)]

These questions will likely be welcomed by the family caregiver who is engaged in providing much health-related care to a loved one. Asking such questions will acknowledge to this caregiver that his or her role is recognized and appreciated. It will also provide the family caregiver opportunity to express and reflect on their needs, which is a therapeutic experience.

Buck and McMillan took the Spiritual Needs Inventory (SNI) developed by Hermann for patients and tested its validity with 410 family caregivers of hospice patients.[57] This 17-item instrument assesses religious needs (e.g., for devotional practices and service attendance), outlook needs (e.g., "think happy thoughts," "be with friends," "see smiles"), and community needs (e.g., knowing about or being with family and friends) (see Table 34.3). The SNI offers a possible method for a standardized approach to family caregiver spiritual screening and assessment.

Assessing Diverse Spiritualities

Spiritual assessment methods must be flexible enough to obtain valid data from persons with diverse spiritual and religious backgrounds. Although the questions and assumptions presented in this chapter will be helpful for assessing most patients living in Western, Euro-American cultures, they may not be applicable for some patients who do not share these presuppositions. For example, some may believe it is wrong to discuss their inner spiritual turmoil as they face death and will refuse to fully engage in the process of spiritual assessment. For example, some Buddhists and Hindus may believe they must be in a peaceful state to be reincarnated to a better state; African American Christians may think it is sinful to express doubts or anger toward God.[85] Framing spiritual assessment in a positive tone may overcome this type of barrier (e.g., "Tell me about how you are at peace now"). Others may assume there is no spiritual reality and therefore decline any questions regarding their "spirituality." This barrier to assessment can be overcome with questions that are void of such language (e.g., "How is your courage?"; see Box 34.1).

For patients who are religious, it is important to remember that no two members of a religious community are exactly alike.[3] For example, one orthodoxly religious person may believe he should never consume any mind-altering drugs, such as morphine, while a less conservative member of the same denomination may understand that such drugs are a gracious gift from God. Although having a cursory understanding of the world's major religious traditions provides nurses with some framework for inquiry, remaining open to the variation of religious experience and expression is essential.

The Next Step: What To Do with a Spiritual Assessment

Interpreting the Data

Even a spiritual screening can generate a lot of information. This information must be processed to identify what, if any, spiritual need exists and to plan spiritual care. Several points can be considered while processing the data. These include:

- What patients tell you at first reflects not how well you have asked a good question; rather it shows how safe and respected the patient feels with you.
- Consider what incongruities exist. Do the affect, behavior, and communication (ABCs) line up?
- Consider the level of concreteness or abstractness in the patient's talk about spiritual matters. Healthy spirituality straddles these opposites.
- Consider how defensive or threatened the patient is by talk about spirituality. Did the patient change the topic? Give superficial answers? Become competitive? Analyze feelings?
- Keep in mind that crises (e.g., illness) expose the gaps in a patient's spiritual development. Did significant events earlier in life stunt the patient's spiritual growth?
- Remember that religion offers a lens for interpreting life. Likewise, when patients tell meaningful stories, legends, or passages from their holy scripture, they are telling you about themselves.
- Reflect on how helpful versus harmful a patient's spiritual beliefs and practices are. Do they create inner anxiety? Do they limit the patient from using other helpful coping strategies?[70]
- Although an in-depth analysis is beyond the scope of most palliative care nurses, having an awareness of the various ways to evaluate what a patient says will help the nurse begin to make sense of the data.

Documentation

Although assessments of physiological phenomenon are readily documented in patient charts, assessments and diagnoses of spiritual problems are less frequently documented. Indeed, a survey of outpatient healthcare professionals in a Christian healthcare organization (which included 217 nurses and other nonphysician clinicians), revealed 80% were of the opinion that the terminally ill should be screened for spiritual distress.[86] Although only 68% of this sample believed spiritual screening data should be documented, there are reasons why spiritual assessments and care should be documented to at least some degree. These reasons include (1) to facilitate the continuity of patient care among palliative care team members and (2) to document for the monitoring purposes of accrediting bodies, researchers, quality improvement teams, and others. Data collected during spiritual assessments are often very private, sensitive material; to document such may breach confidentiality and thus pose an ethical dilemma. As with other sensitive charted information, nurses must treat spiritual assessment data with much respect and observe applicable privacy codes.

Formats for documenting spiritual assessments and diagnoses can vary. Some institutions encourage staff to use Subjective, Objective, Assessment, Plan (SOAP) or similar formatting in progress notes shared by the multidisciplinary team. Others have developed quick and easy checklists for documenting spiritual and religious issues. Perhaps an assessment format that allows for both rapid documentation and optional narrative data is best. However, merely documenting one's religious affiliation and whether one desires a referral to a spiritual care specialist certainly does not adequately indicate a patient's spiritual status and need.

A few studies provide evidence about how clinicians document spiritual screening, history, or assessment findings. Whereas a couple of studies examine documentation of spirituality/religiosity in the ICU setting,[87,88] three studies provide indications about how frequently it occurs in palliative care settings.[89–91] The strongest evidence comes from Kamal et al.'s[89] multisite chart review (N = 1,989). They found that rates of documentation regarding spiritual concerns at the first palliative care visit varied significantly by whether the clinical setting was acute or non-acute. That is, in acute care settings, only 17% completed a spiritual history (e.g., 0% in emergency departments), whereas it occurred 47% of the time in non-acute setting (e.g., 70% in the home setting). Whereas the data in Kamal et al. were collected in the Southeastern United States, O'Reilly and colleagues[90] observed in an Irish tertiary setting palliative care service that spiritual screening documentation occurred only in 23% of patient records (although 91% of patient religious identity was documented). After an intervention that introduced a collection of palliative care assessment tools (including the FICA for assessing spirituality), these researchers brought the spirituality documentation completion rate up to 82%. In contrast, an audit of charts of patients never seen before in a New England outpatient palliative care clinic revealed that 80% of 142 charts included "emotional/spiritual" assessment information; however, only 13% recorded any recommendation related to these data. A chart review of 144 ICU patient records likewise observed that only about half had any spirituality data documented.[87] This documentation, however, rarely included a description of discussions clinicians had with patients about spiritual concerns. Indeed, another analysis of chaplain entries in ICU patient records concluded that they tended to use "coded" language (i.e., jargon other clinicians might not understand), provided description (rather than interpretation), and tended to be passive about follow-up plans for the patient.[88] In concert, these findings indicate that spirituality may be infrequently documented; however, institutional interventions can increase the rate of completion and documentation.[39,90,92]

Organizational Approaches to Supporting Spiritual Screenings and Histories

Evidence reviewed indicates that spiritual screening, histories, and assessment are often not completed and/or not documented. For example, although 89% of outpatient clinicians in the Christian healthcare organization previously cited were willing to conduct spiritual screenings (40% often or very often), only 11.5% did so often or more often.[86] When exploring the frequency of spiritual screening from a patient viewpoint, very few patients in an urban oncology outpatient clinic (N = 727) reported that clinicians had asked about their spiritual beliefs (17%) or needs (11%), and 23% responded that their spiritual needs were not being met.[10] Even though clinicians typically accept that persons with terminal illness should be assessed for spiritual needs, few act on this belief.[86] Clinicians may worry that spiritual screening and history-taking may be misinterpreted as religious proselytization, they may perceive that they lack time or skill, or they may believe it is not within their purview or feel discomfort with broaching the topic.[26,27]

Given this incongruity between the philosophy of palliative care that embraces the importance of spirituality and the delivery of care that evolves from spiritual screening, history-taking, or assessment, several healthcare organizations have implemented processes to correct for this discrepancy.[39,46,92,93] Two American quality improvement projects were designed to increase the documentation of palliative care patient spirituality.[39,92] Lamba and colleagues inserted a "SmartPhrase" in the electronic health record (EHR) to prompt palliative care clinicians to include certain aspects of an assessment.[92] This included a prompting for "psychological" symptoms that included spirituality-related concerns. Gomez-Castillo and team engaged stakeholders to identify barriers to completing the FICA history in their palliative care service. They next initiated an expectation that every new patient during 1 of the first 3 visits would be co-visited by a chaplain. Both initiatives led to significant increases; the FICA documentation increased from 49% to 72% (N = 79).[39]

Many healthcare systems have instituted a screening tool comprising a few screening questions that are embedded in the standardized admission assessment, typically electronically. The electronic medical record system is sometimes designed then to allow the clinician to not only insert patient responses to screening questions (sometimes requiring the nurse to translate a qualitative response into a yes/no tick box response), but also to submit a referral or add to a care plan if a spiritual need was identified. Skalla and Ferrell completed a pilot study of outpatients receiving cancer care (N = 29) to learn how feasible it would be for these patients to complete a spiritual assessment online.[93] Patients completed 49 items that included items from existing scales on a laptop. Whereas some patients did complete the questionnaires, 22 declined to participate. This observation underscores the need for spiritual screening that is brief and clinically relevant.

Conclusion

Spirituality is an elemental and pervading dimension for persons, especially for those receiving palliative care. Assessment of spirituality, whether in an initial screening, a history, or more complex assessment, is essential to effective and sensitive spiritual care. Indeed, spiritual assessment is the beginning of spiritual care. While the nurse questions a patient about spirituality, the nurse is simultaneously assisting the patient to reflect on the innermost and most important aspects of being human. The nurse is also indicating to the patient that grappling with spiritual issues is normal and valuable. The nurse also provides spiritual care during an assessment by being present and witnessing what is sacred for the patient.

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CHAPTER 35

Spiritual Care Intervention

William Rosa

Key Points

- Spiritual care is an essential component of whole-person care, providing healing through authentic presence and the creation of a caring-healing, spiritually safe environment.
- Employing the skills to effectively identify and meet a patient's and family's spiritual care needs requires a clear intentionality, compassion, and the integration of multiple modalities that tend to the spirit through all ways of being, doing, and knowing.
- Holistic spiritual care allows the ones being cared for to feel fully self-expressed, address the source of their pain at spiritual-existential levels, and embrace their humanity in a way that frees them to explore meaning and purpose in their life.
- Love is the ultimate spiritual care intervention.

Introduction

"Spirituality is inextricable from the sacredness of nursing practice. Both are a search to know [the Sacred] through the continued healing of self and others. Both create a state in which we potentiate and are present to an experience of Oneness."[1(p. 24)]

The following definitions will be useful in reading this chapter on spiritual care interventions:

- *Spirituality*: "The essence of our being. It permeates our living in relationships and infuses our unfolding awareness of who we are, our purpose in being, and our inner resources. Spirituality is active and expressive. It shapes—and is shaped by—our life journey. Spirituality informs the way we live and experience life, . . . spirituality is expressed and experienced through living our connectedness with the Sacred Source, the self, others, and nature."[2(p. 135)]
- *Spiritual care*: "That care which recognizes and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship, and moves in whatever direction need requires."[3(p. 6)]
- *Spiritual well-being*: The depth of a person's ability to find purpose and meaning; feel connected with self, others, the Sacred, and nature; balance the energy required for rest and recreation; and integrate opportunity for reflection on the journey.[2]
- *Religion*: "An organized system of beliefs regarding the cause, purpose, and nature of the universe that is shared by a group of people, and the practices, behaviors, worship, and ritual associated with that system."[2(p. 135)]

Case Study: A Patient Seeking Spiritual Comfort, Part I

Jacob is a 43-year-old man diagnosed 7 months ago with metastatic stage IV pancreatic cancer to his liver and bilateral lungs. "Jake," as he prefers to be called, has been married to his high school sweetheart, Anne, for the past 20 years. The couple had three children, daughter Pat (age 16), daughter Marcia (age 10), and son Paul (age 6). Jake's parents, Mary and Jake Sr. were both in their 70s and maintained a close relationship with their children and grandchildren. Jake had one younger and estranged brother, Mark. There was no additional family support except several close friends. Jake had been employed as a financial analyst for the past 12 years and was still working. Raised as a Catholic, he had strong aversions to organized religion, and his faith was "not important" to him. He did not appear to be at peace with his illness or his grim prognosis of 6 months to 1 year. Jake had no other significant medical or surgical history, had never smoked, and denied illicit drug or alcohol use. Jake's last dose of chemotherapy was 2 weeks ago, and now he has presented to the urgent care center of an acute care hospital for pain crisis and increased dyspnea on exertion for the past 48 hours prior to admission. The palliative care team has been consulted for assistance with pain and symptom management. The admitting nurse, Patrick, understood the importance of integrating spirituality and spiritual care into his assessment and plan.

Spirituality and Spiritual Care

Spirituality is one of the primary unifying forces of the human experience. It inextricably links us as human beings of the global village across cultures, continents, faith traditions, genders, socioeconomic differences, and the continuum of wellness–illness.[4] The spiritual journey is a vulnerable exploration of the mystery of life that yearns to seek meaning and purpose and to embrace both the light and shadow sides of one's nature. Tending to the spiritual needs of another is one of the most privileged responsibilities of nursing; a task rooted in compassion and love that elevates nursing's role in healing and alleviating suffering.

Spiritual care addresses the suffering inherent to the human experience.[5] This care seeks to mitigate the deeply painful consequences of loss (of autonomy, relationships, health, etc.), hopelessness and/or isolation, recognizing one's mortality, or feeling unseen, unheard, unacknowledged, or voiceless.[6] In order to deliver and sustain ethically sound spiritual care, the nurse must learn to integrate personal beliefs regarding spirituality with the professional responsibility of service and a focus on patient and family needs.[7] This is a substantial request for it asks the nurse to forge increased self-awareness and equanimity in his or her professional relationships, surrender judgments, and commit to healing the other with respect for that person's subjective beliefs, practices, questions, uncertainties, worries, joys, sadness, and perspectives on life, living, dying, and death.

Spiritual care is not a linear action item, but rather a circular, iterative process that emerges and evolves through relationship-building: a dance between continual assessment and intervention, reassessment, and the delivery of additional interventions.[8] The very practice of spiritual assessment is, in fact, an intervention—it is a time of "being with," asking the more challenging questions about the mystery of life, and bearing witness to the human experience of making meaning and finding purpose. Box 35.1 provides a list of spiritual care questions that provide a starting point for guiding the encounter.[9] Not all questions must be asked, as the answers given will guide next steps. The human spirit is dynamic and ever-changing, and the care provided must flow with the spiritual currents of another's tide. While the palliative care nurse plays an influential role in spiritual care, it is vital to know when to consult the experts. There are certain questions, found in Box 35.2, that, when asked by a patient or family, suggest the need for a chaplain referral.[9] Spiritual care requires as much attention as the physical, psychological, and social domains of care,[5] and when this dimension is nurtured in integrity, it continually influences the nurse's ways of being, doing, and knowing in this sacred and privileged work.[8]

Box 35.1 Spiritual Care Questions from Nurse to Patient

- How is your spirit doing today?
- Are you scared?
- What are you most afraid of?
- What makes life worth living?
- Is there anything you haven't done that you need to do?
- What do you hope for?
- What is your deeper hope?
- Is there anything worse than death?
- What are you most proud of in your life?
- Do you have regrets?
- Do you need to forgive anyone?
- Do you need to ask forgiveness from anyone?
- What will your legacy be?
- What do you love most about your life?
- Are you at peace?

Source: Adapted from Reference 9.

Box 35.2 Questions/Statements by the Patient Requiring Chaplain Referral

- What have I done to deserve this?
- I pray but I'm still sick.
- I used to believe in God, but now I'm not so sure.
- I feel like all hope is gone.
- No one has ever accepted me because I'm different.
- How will my family get along without me?
- What did my life mean?
- What is there left to care about?
- No one understands.
- I'm scared.

Source: Adapted from Reference 9.

Holism, Theory, and Intentionality: Prerequisites for Spiritual Care

Spiritual care calls the nurse to fully engage with the human being at hand and to attend to the patient and family from a holistic stance. *Holistic nursing* is " all nursing practice that has healing the whole person as its goal and honors relationship-centered care and the interconnectedness of self, others, nature, and spirituality"; it seeks to optimize one's level of health and well-being, and it integrates caring-healing modalities, or what may be referred to as complementary and alternative medicine (CAM).[10(p. 3)] Integrative nursing principles include assumptions that human beings are whole systems, inseparable from their environments; human beings have the innate capacity for health and well-being; nature has healing and restorative properties; care is person-centered; practice is informed by evidence and a full range of therapeutic options based on need and context; and that care of both self and other are of tantamount importance.[11] Furthermore, a holistic lens requires nurses to employ all ways of knowing: personal, empirical, sociopolitical, ethical, aesthetic, and "not knowing"—being open to the emerging scenario without preconceptions or judgments.[10]

The annals of nursing theory offer myriad perspectives on the holistic design of spiritual care interventions. For example, Watson's Human Caring Science posits that the moral foundation of nursing lies in caring-healing relationships and the promotion and assurance of human dignity, first and foremost and at all costs.[12,13] Human Caring Science suggests that the physical form of the human being is really embodied spirit, and so, in caring for another, the nurse is in direct contact with the human spirit. In this worldview, *all* care is spiritual care. Table 35.1 provides the Caritas Processes, the ethical guideposts of Human Caring Science, accompanied by reflection questions for nurse self-development.[14] Reed's Theory of Self-Transcendence addresses the everyday practicality of spirituality that is accessible as the patient expands intrapersonally (greater awareness of personal values and beliefs), interpersonally (connection with others, nature, and environment), transpersonally (relation with extraordinary dimensions beyond the tangibles of the physical plane), and temporally (integration of past and future to give meaning to the present).[15] Parse's

Table 35.1 Caritas Processes with self-reflection questions

Ten Caritas Processes	Reflective Caritas Inventory for self-healing and development
1. Embrace altruistic values and practice loving kindness with self and others.	Have I set an intention of self-caring and self-kindness today? Have I centered myself with an act of self-love so that I might be restored?
2. Instill faith and hope and honor others.	Am I clear about what I have faith in? Have I reminded myself of the people, places, and spaces that give me hope?
3. Be sensitive to self and others by nurturing individual beliefs and practices.	Have I responded to my thoughts and feelings today with gentleness, knowing that my experience is unique and sacred?
4. Develop helping-trusting-caring relationships.	Have I empowered myself to release toxic relationships and embrace supportive connections in my life with truth and vulnerability? Just for today, can I trust myself to be there for me?
5. Promote and accept positive and negative feelings as you authentically listen to another's story.	Have I authentically accepted my own story? Do I fully embrace all aspects of who I am; the positive and the negative, the light and the dark?
6. Use creative scientific problem-solving methods for caring decision making.	Do I recognize how creative I am? Have I celebrated my "me-ness" in how I approach, interact with, and inspire this world around me?
7. Share teaching and learning that addresses the individual needs and comprehension styles.	Am I forthcoming about my needs at work and at home? Do I remain flexible and energized or easily tire with my old patterns of rigidity?
8. Create a healing environment for the physical and spiritual self which respects human dignity.	Have I physically or energetically touched my heart today? Have I connected with my own heartbeat; the same heartbeat shared by all of humanity? Have I admitted to myself that my healing starts within?
9. Assist with basic physical, emotional, and spiritual human needs.	Have I paused to attend to my own hunger? My anxiety? My worries? My frustrations? Do I recognize my individual needs as valid?
10. Open to mystery and allow miracles to enter.	Can I release the need to be certain, to explain, defend, protect, and define? Can I surrender to the moment and allow life to unfold as it will?

Source: Adapted from Reference 14.

Humanbecoming School of Thought suggests that health is a dynamic process that develops as humans choose the way they live and that nurses attend to the human experience as unique and unpredictable.[16] It is in this unfolding space of being and becoming referenced by Parse, which may be vulnerable or uncomfortable for the patient, that intelligent spiritual care becomes essential.

Intentionality is a cornerstone of spiritual care intervention. It can be defined as "holding the heartspace with compassion in our knowing, doing, and being while performing an action."[10(p. 24),17,18] Mindless behaviors enacted by the nurse may trigger biocidic (life destroying) repercussions, such as anger, despair, or a sense of decreased well-being.[13] However, mindful caring-healing engagement on behalf of the nurse may be biogenic (life-giving) for all involved and, ultimately, fosters spiritual freedom.[13] As the nurse co-creates with the patient an experience where such freedom is possible, one intention might be to ground nursing practice in an ethic of *evolving human-centered care*:

> compassionate and empathic care that responds, attends, and conforms to the human as a living, breathing, evolving experience; human as fluctuating phenomenological being of engagement; human as history, as story, and as narrative; human as presence, emergence, and possibility; human as fellow sojourner; human as caring-healing; and human as LOVE.[19(p. 336)]

In this way, compassion becomes the currency for the humanistic delivery of spiritual care.

Compassion in Action

Compassion can be defined as a "virtuous response that seeks to address the suffering and needs of a person through relational understanding and action."[20(p. 195)] It is quite possibly the single most sacred virtue in the history of humankind and the central common aspect of almost all faith traditions.[21] It is a vessel for the expression of the human spirit. The literature suggests that compassion, as well as its absence, yield significant consequences on those being cared for.[22,23] While compassionate behaviors help patients to trust their providers and attain increased feelings of satisfaction and emotional support,[24] further studies are needed to identify how best to train providers regarding compassion and create tools for the accurate measurement of compassionate care-related outcomes.[25–27]

Sinclair and colleagues[20] identified seven categorical elements of compassion with related themes identified by patients: (1) virtues (genuineness, love, openness, honesty, authenticity, care, understanding, etc.), (2) relational space (patient awareness, engaged caregiving), (3) virtuous response (knowing the person, person as priority, beneficence), (4) seeking to understand (seeking to understand the person and their needs), (5) relational communicating (awareness of demeanor, affect, behaviors, engagement), (6) attending to needs (compassion-related needs of body, mind, and spirit, taking action in a timely manner to alleviate suffering), and (7) patient-reported outcomes (alleviation of suffering, enhanced well-being, and perception of enhanced care).

Compassion in theory and in the face of significant clinical time constraints may often feel elusive or idealistic, but compassion in action is possible—an achievable moral imperative of nurse-delivered spiritual care.[9,28] Notable journalist Krista Tippett has identified component parts of compassion that make it tangible: the observable actions that bring it to life in the realm of human interaction.[29] These component parts—presence, generosity, forgiveness, empathy, kindness, mystery, beauty, and tenderness—serve as catalysts for spiritual expression and help metabolize the experience of compassion in human relationships.

Presence. The concept of *presence* can be defined as "the essential state or core of healing; approaching an individual in a way that respects and honors her or his essence; [being with rather than doing to]."[30(p. 55)] In order to be present and maintain a state of authentic presence, the nurse might consider cultivating a deeper level of self-inquiry and self-knowledge in order to release distractions and engage from a place of being centered and grounded.[31] Being intentional with one's presence is a cultivated and practiced skill that allows the nurse to work from a space of clarity by releasing limiting judgments, embracing personal fears about illness and death, and being fully available to the needs of the patient and family.[32]

Generosity. When providing spiritual care, generosity does not refer to the donation of material or financial resources, but rather being generous with one's context.[28] Each person generally creates a context or lens through which they see the world. When nurses engage in spiritual care intervention, they generously suspend their context in order to immerse in the context and worldview of another.[33] Contextual generosity ensures socially conscious care delivery. It requires time and attention to ensure spiritual care does not fulfill the nurse's agenda, but rather meets a patient and family where they are.

Forgiveness. The need to forgive or ask for forgiveness are tasks that often arise for patients experiencing serious illness or at end of life. One of the most challenging roles for palliative care providers is to facilitate forgiveness between patients and families.[34] The act of forgiveness may reflect a process and attitude rather than a formal reconciliation.[35] Patients may need to forgive themselves, their bodies, others, parents, children, siblings, employers, God, or the world in order to return to a sense of wholeness and well-being.[36] Providing space for forgiveness to occur is a nursing spiritual care intervention and an exercise of compassion.

Empathy. In order to truly meet a patient's needs, nurses must demonstrate increased sensitivity to another's views of the situation at each point along the encounter and articulate concern and empathy to improve communication.[37] Effective empathy requires attention, curiosity, and imagination; the acknowledgment of complex and shifting goals of care; and the willingness of a nurse to find out what has been misunderstood or misperceived within the relationship.[38] It is through empathic communication, both verbal and nonverbal, that the nurse may find a balance between validating the facts of a scenario and reframing and re-establishing hope.[39]

Kindness. Loving kindness is a foundational principle of all faith traditions and, in fact, it has been shown that many patients will accept a clinician's offer of prayer if that clinician demonstrates genuine kindness and respect.[40] Offering prayer is most appropriate for patients who have expressed a desire to pray with others and may be detrimental for patients who are nonreligious or do not share the same beliefs as the nurse. Whether in times of prayer, silence, or attending to clinical needs, kindness informs the quality of time spent in the nurse–patient relationship and serves as a reminder of the nurse's regard for the patient's well-being. Kindness as an act of compassion calls for sensitivity and patience and a self and system evaluation of *how* care is provided. Kindness is deeply related to beneficence, the ethical principle of "doing good," and evokes questions regarding social justice equity in health care and *how* care is rendered.[41] What does the doing of good mean without the demonstration of kindness?

Mystery. As discussed earlier, the realm of spirituality and spiritual care revolves around the mysteries of life and a desire to derive meaning. There is an inherent mystery to human existence: something in each human being—but also something between each human being—waiting to be unlocked and found and seen. Allowing what is mysterious in one's self to meet with and know the mystery in another is a courageous act that promotes compassionate relationships.[28] And in that moment of connection and vulnerability—something new is nurtured—an emerging relational mystery comes alive by being in partnership for the journey. Compassion cannot exist in an arena of deterministic thinking. In fact, its most substantial barriers are restrictions, such as agendas, pressure, and time limits, but being available to the mystery allows compassion to resonate and grow.

Beauty. Embracing beauty in a way that awakens compassion asks us to move beyond the empirics to simply become aware of the uniqueness of another in this moment. The practice of beauty and dropping into an aesthetic way of knowing connects human beings to the fragility of life. It is in this fragile place that compassion is given the natural playground to express itself; not from a place of outcomes-focused intervention, but from a simpler place—a place of being available to the beauty in the moment.

Tenderness. Kahlil Gibran wrote of "knowing love as the pain of knowing too much tenderness." In this way, tenderness becomes one's connection to love and an outward demonstration of love for both self and others. Tenderness brings all the other components of compassion together. Tenderness as a way of staying present, generous, forgiving, empathic, kind, and being open to the mystery and beauty emerging in the moment; tenderness as a way of being, doing, and knowing, and as a demonstration of the deepest regard for another's spirit.

Transpersonal Development and Transpersonal Nurse Coaching

There is an aspect of human consciousness that transcends the boundaries of the ego identity and is a part of something greater: the aspect of self that recognizes connection, unity, and oneness with all other beings, the larger environment, and with spirit—this is the *transpersonal.*[42] Scientists posit that all human beings are a part of one mind and one consciousness at a greater level beyond rational understanding.[43] Caring for the transpersonal domain of another's well-being gives the nurse direct access to their spirit for the purpose of returning to right relation. *Transpersonal development* suggests that every person has within his or her own deeper nature the resources required to be in harmony with life as it is and the capacity to open his or her personality and discover his or her unique and inherent healing capacities.[44] Fostering the discovery of transpersonal resources of peace, wisdom, purpose, and oneness in another aids them in moving through crisis and awakening to new healing possibilities.[45]

The holistic arena of professional nurse coaching trains providers to develop literacies in spiritual intelligence, which often arises from the practices of authentic presence and deep listening.[46,47] Transpersonal nurse coaching (TNC) is a specialty within professional nurse coaching that specifically aids patients in moving from fear to choice, opening their personality, and moving from separateness to oneness.[48] According to Schaub,[48] the basic principles of TNC include:

- A focus on pro-active health promotion, helping patients understand how to awaken to their deeper resources in difficult times.
- The nurse is not "fixing" or "suggesting," but rather aiding patients to awaken to what already exists within them.
- Awareness techniques provided are safe, effective, and proven and are applicable to all cultures and belief systems.
- The nurse assists patients to develop subjective meaning related to their experiences of inner peace, wisdom, life purpose, or oneness.

The tools of the transpersonal nurse coach include guiding patients through awareness practices, deep relaxation, techniques that help to release tension throughout the body, and quiet moments of reflection to help them identify and release personal triggers, unresolved feelings, spiritual pain, and body-mind-spirit disconnection.[44,45,48]

Modalities: One Spirit, Many Ways

Nurses may use a wide range of modalities to access the transpersonal domain and spiritual nature of another.[8] Table 35.2 shows various modalities for tending the human spirit in health and healing. Quinn suggests that, regardless of the origin or starting point, the entire body, mind, and spirit is affected each time a modality is applied.[8]

Learning modalities is an excellent opportunity for palliative care nurses to expand their knowledge. It is also a chance to consult and collaborate with experts in integrative medicine when available. Such modalities include energy healing—tending to the

Table 35.2 Modalities for tending the human spirit in health and healing

Approaches to tending the spirit through the individual, inner experience	***Approaches to tending to spirit through the body***
Spiritual practices from one's religion or as given by spiritual guides	Performing ritual practices of one's religious tradition or spiritual path
Meditation consistent with patient beliefs, experiences and desires, for example:	Mindful eating
	Mindful exercise/movement work
Simple breath meditation	Fasting
Zen	Yoga
Vipassana	Pranayama breathing
Contemplative practices, such as Centering Prayer	Walking meditation, including the Labyrinth
Spiritual reading and/or spiritual study	Sacred dance, including Dances of Universal Peace
Integral Inquiry practice with "Big Questions"	Listening to or making music
Cultivating deeper self-awareness	Singing/chanting/repeating mantras
Forgiveness practices	Emotional Freedom Technique
Prayer of all varieties, both active and listening	Tai Chi
Reflective journaling	Qi Gong
Imagery and visualization	Mindful cooking for self and loved ones
Writing/reading poetry	Viewing and/or making Art
Any inner activities that bring people closer to their spiritual ideal, by whatever name/language.	*Any physical activities that bring people closer to their spiritual ideal, by whatever name/language.*
Approaches to tending the spirit through the shared inner experience between/among people	***Approaches to tending to spirit through natural, social, cultural, and institutional environments***
Sitting in Sacred Space with nurse and allowing the questions to arise and be met	Seeking/using appropriate referrals
	Being in nature
Spiritual direction	Being with animals and pets
Group spiritual direction	Organized religious/spiritual services/celebrations
Pastoral care/counseling	Working for social change
Spiritually oriented therapy	Participating in group service activities and causes that feed the soul/spirit
Centering Prayer group	Gardening
Being with loving family/friends	Creating/utilizing Sacred Space
Support groups	Caring for the environment in meaningful ways
Ministry of availability – being willing to be fully present to others who are struggling	Loving-kindness practice in work and other outer, system settings
Seeking healing in broken relationships	*"Anything you do every day can open into the deepest spiritual place, which is freedom."*
Loving-kindness meditation practice	—Rumi
Any shared inner activities that bring people closer to their spiritual ideal, by whatever name/language	

Source: Reprinted with permission from Reference 8.

chakra system or subtle energy body (i.e., Reiki, healing touch)[49]; relaxation—shown to decrease pain and anxiety, improve immune system function, increase pain medication efficacy, and improve a sense of well-being (i.e., biofeedback, meditation, mindfulness, self-regulation)[50]; imagery—bridging connection between body, mind, and spirit (i.e., guided imagery, visualization)[51]; touch- and hand-mediated therapies—shown to decrease fear, anxiety, and feelings of loneliness or isolation (i.e., massage therapy, reflexology, therapeutic touch)[52]; creative expression—fostering acceptance of uncertainty and developing resilience (i.e., improvisation, narrative storytelling, laughter, song, dance, painting)[53]; and aromatherapy—the medicinal use of essential oils through olfaction or topical application to treat pain, infection, and alleviate intense emotions or spiritual distress (i.e., use of oils such as bergamot, true lavender, sweet basil, and sweet marjoram for spiritual distress).[32,54]

The Power of Ritual

Rituals, such as rites of passage, the use of religious or spiritual symbols, and precise, repetitive acts, have been used throughout time to garner personal or social identity, relieve anxiety, discover inherent cultural wisdom, and provide stability amid transition and change.[55] While rituals tend to invoke a religious context, there is a healing potential in the practice of everyday rituals, which may be particularly comforting to patients who have struggled with chronic disease, are confronting the symptoms and experiences of serious illness, or are entering the dying process.[9] The nurse–patient relationship is the quintessential opportunity for co-creating compassionate rituals, given the intimate and interpersonal dynamics of nursing care.[56] There are simpler rituals, such as being present and caring while bathing and dressing a patient, administering medications, or simply listening while the patient reminisces, which may enhance spiritual well-being. And there are the rituals of engagement and disengagement that may be more challenging, such as preparing to greet or leave a patient in spiritual distress at the beginning or ending of a shift or the grief rituals that nurses and interprofessional teams develop to pay respects to a patient who has died.[57] Praying with patients, or remaining fully available during their prayers, can be an empowering ritual symbolizing a communion with the Sacred and can be an expression of a relationship with the Sacred.[58] However, as mentioned earlier, this intervention should always be delivered in response to a patient's need or desire.

Conscious Dying: Holding Sacred Space at the End of Life

Conscious dying provides a guiding ethic for nurses to hold healing and sacred space for those at end of life in order to provide the highest quality and spiritually guided humanistic care. The framework of conscious dying is rooted in a caring science ontology[59] and recognizes the nurse as a primary healing instrument: a doula who births and guides the sacred passage of the dying one.[19] The Conscious Dying Principles and Practices (CDPs) are listed on the left of Table 35.3 with reflective questions for nurses listed on the right to assess the readiness of healthcare systems to create optimal healing environments at end of life.[60] The CDPs tend to the physical plane and open awareness regarding the spiritual dimension, laying the groundwork for a conscious dying experience. The Subtle Energy Realms (SERs) listed in Box 35.3 move the nurse from a space of doing toward deeper ways of being and knowing.[61] "Rather than principles, they are really stages or phases within the dying process that appear—or not—as the human being turns

Table 35.3 Conscious Dying Principles and Practices with self-reflection questions

Conscious Dying Principles and Practices	Reflective conscious dying inventory for systems healing and development
1. Increase beauty, pleasure, contentment.	Do systems provide space for beauty? Do I see patients having time to value and partake in pleasure?
2. Provide emotional and spiritual support.	Have we as a system attended to the spiritual needs of the patient today? Has the patient been emotionally seen, heard, and acknowledged today?
3. Initiate conversations about the dying process.	Are my colleagues and I comfortable talking about death and dying? Is the patient aware that death is a process?
4. Practice self-care to prevent burnout and compassion fatigue.	Are the connections clear between my own self-care and the care I provide for my patient? Can I co-identify with the vulnerability of my patient and gently attend to my own self-care needs?
5. Demystify the stages of the dying process.	Am I clear about the mental-emotional-spiritual stages of the dying process? Is the patient attended to throughout the spectrum? Is there a dissonance between my knowledge, system-wide protocols, and patient needs?
6. Acknowledge mysteries, miracles, and unexplained events.	Are systems willing to bear witness to the mystical? If yes, am I able to validate and share the patient's subjective experiences within this realm despite my personal discomfort?
7. Learn how to be with intense emotions.	Do systems "lean into" the difficult emotions? Can we guide providers to invest in and engage with the actual, moment-to-moment story of our patients and families?
8. Honor others' beliefs without them threatening your own.	Are systems able to release agendas selflessly to support the patient's beliefs with flexibility? How can we facilitate and empower individualism through compassionate advocacy and empathy?
9. Be a steward of conscious deaths.	Do we see systems pave the path for peaceful transitions of integrity? How can we humanize dying by creating an environment of dignity and adequate, anticipatory preparation?
10. Attend at bedside – no one dies alone.	Does the infrastructure of the systems allow for sustained human caring? How can we systematically prepare in meeting the undeniable need to bear witness?

Source: Adapted from Reference 60.

Box 35.3 Subtle Energy Realms

1. Acknowledge mysteries.
2. Be open to miracles.
3. Acknowledge unexplainable events.
4. Be aware of nearing death portals.
5. Allow for the return of the ancestors.
6. Validate the presence of departed loved ones.
7. Honor the waiting in between.
8. Protect the time of crossing over.
9. Imagine breaking into light.

more inward toward the realm of spirit and invisibility . . . into the spiritual-energetic realms we cannot physically see. Naming these subtle energies is really naming the realms/phases that are inherent in the transition [toward death]."[19(p. 339)] This philosophy asks nurses to bear witness to another's suffering without interruption, surrender the need to fix or change what is happening, and to be in touch with one's own grief and suffering to be there for another in theirs.[9] Conscious dying asks the nurse as primary healing instrument to remain humble, curious, willing, reverent, and present to the unfolding of life and death, remembering that suffering is not always reflective of discomfort and may be a sign of the deeper processes of personal and spiritual growth.[62]

Case Study: A Patient Seeking Spiritual Comfort, Part II

Jake was admitted to the medical floor for pain and symptom management and observation. Jake reported improved pain and dyspnea control after medication administration. Patrick, his nurse, took a mindful breath, asked permission to sit at the foot of Jake's bed, and held the space for a shaken-up Jake. Jake shared that his disease had brought to the forefront all unresolved issues. He had recently had multiple calls with his estranged brother and taken accountability for past transgressions. Mark had forgiven him and they had found peace in each other.

Jake said to Patrick, "I am not a religious man. But I am scared for my wife and children. Will you pray with me?" Patrick replied, "I will sit here with you and share your prayers." Jake began to ask God for the protection of his family since he knew he would not be with them forever. Patrick, who had trained in Transpersonal Nurse Coaching, offered to lead Jake through a deep relaxation exercise, which he gratefully accepted. Patrick asked Jake to follow the inward and outward flow of his breath for a few moments, helped Jake to find and release tightly held tension in his back and shoulders, and then asked, "What is your hope?" Jake responded, "That I won't be in any pain." Patrick paused for a minute or two and then added, "What is your deeper hope?"[44(p. 110)] And Jake answered, "That I will be loved." Patrick finished by applying some true lavender oil to a cotton swab and encouraged Jake to take some deep breaths while holding it under his nose. As Jake opened his eyes, he thanked Patrick for being so kind and compassionate.

Jake declined over the next 3 days, eventually becoming verbally unresponsive. Patrick shared with the family that Jake's deepest hope was that he would know love in his final moments. He stood with them as they grieved in anticipation and remained fully available, choosing not to try and fix or change their suffering. Patrick ensured Jake's favorite music was playing softly, and he encouraged Jake's wife to put out pictures of the family to fill the room; he placed flowers by the bedside and covered Jake with his favorite blanket from home. As Jake mumbled or spoke to "people who aren't there," Patrick reminded the family that this was all natural. The Therapeutic Touch practitioner stopped by and taught the family how to comfort Jake through touch. The chaplain returned several times to pray with the family.

When Jake died a few hours later, Patrick was there to witness the pain of Jake's loved ones. His mother collapsed to the floor and Patrick lifted her, putting her in the bed so she could "hold her baby." Later, as Patrick cleaned and prepared the body, he placed his hand on Jake's heart and carried out his own grief ritual of saying good-bye. After a quiet, centering pause, Patrick leaned forward and whispered in Jake's ear, "You are deeply loved and never forgotten."

Love: The Final Word

It is rare to hear the term *love* used in healthcare today. But it continues to be the universal language of humanity; the surest way toward peace and the alleviation of suffering; the most enlightened tool in the healing of another. Goldin calls the "practice of nursing" the "practice of love of humanity."[63(p. 289)] Love is the moral/ethical foundation of nursing: the holy work of touching bodies and spirits and souls.[63] Researcher-storyteller Brené Brown writes,

> We cultivate love when we allow our most vulnerable and powerful selves to be deeply seen and known, and when we honor the spiritual connection that grows from that offering with trust, respect, kindness, and affection. Love is not something we give or get; it is something that we nurture and grow, a connection that can only be cultivated between two people when it exists within each one of them—we can only love others as much as we love ourselves.[64(p. 26)]

And that is the essence of spiritual care.

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CHAPTER 36

Meaning in Illness

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Key Points

- Finding meaning in illness is an important issue when facing the end of life.
- The process of finding meaning in illness involves a journey through sometimes very difficult transitions.
- A terminal illness can greatly impact the patient–caregiver relationship.
- It is essential for nurses to experience their own journey in the dying process and bring with them an openness to be transformed by it.

Introduction

"In the driest whitest stretch of pain's infinite desert, I lost my sanity and found this rose."[1] Is it possible to adequately articulate and give definition to meaning in illness? Or is meaning in illness better described and understood through using symbolism and metaphors like the poem by Galal al Din Rumi?[1] To try to define that which is enigmatic and bordering on the ineffable seems almost sacrilegious. The unique journey of finding meaning in illness that is faced by patients and their families would seem to be diminished by a process that relegates the experience to the confining boundaries of language.

Is it that patients seek to find meaning in illness, or is it that they seek to find meaning in the life that is now left, in relationships, and in all that we value? Do patients seek to find meaning in illness itself as an isolated event or that which is beyond the illness, such as how to live out this newly imposed way of life? Terminal illness often forces one to reappraise the meaning and purpose of life. If one allows space in life for the process of meaning in illness to unfold, one then moves from the superficial to the profound.

Terminal illness also compels one at some point to look directly at death, yet at times patients resist getting in touch with the feelings that arise. Everything in a person seeks life, hopes for life, and denies death. There is something very cold, very unmoving, and very disturbing about it all. Does the end of one's human existence on Earth need to be the sole metaphor for death?

Although end-of-life care has greatly improved, there is still much work to be done to provide the dying patient with personal, compassionate, and comprehensive care. It is not enough for nurses to solely rely on the nursing process. The patient's illness odyssey beckons the nurse to go beyond assessment, diagnosis, intervention, and evaluation to a place of vulnerability, in a way that allows for a shared connectedness unique to each patient–nurse relationship. Nurses need to be willing to use feelings appropriately as part of the therapeutic process. Separating oneself from touching and feeling for purposes of protection only creates more vulnerability because one's emotions are placed in isolation. Nurses can be a catalyst for helping the patient and family find meaning in the illness, and, in the process, they, too, can define or redefine their own meaning in life, illness, and death.

Meaning Defined

Johnston-Taylor[2] presents several definitions for *meaning* (Table 36.1). In the dictionary,[3] one finds *meaning* defined simply as "something that is conveyed or signified" or as "an interpreted goal, intent, or end." But it is the etymology of the word "mean" that helps nursing come to understand the potential for supporting patients in the process of finding meaning in their lives, even as they face death. "Mean" comes from the Old English *maenan*, "to tell of." One does not find meaning in a vacuum; it has everything to do with relationships, spirituality, and connectedness. While the process of finding meaning depends greatly on an inward journey, it also relies on the telling of that journey. This may involve language as in a narrative or in story-telling, but it may also be conveyed by the eyes, through the hands, or just in the way the body is held. Frankl[4] reminds us that the "will to meaning" is a basic drive for all of humanity and is unique to each individual. A life-threatening illness begs the question of meaning with a new sense of urgency and necessity.

Cassell[10(p. 67)] states that "all events are assigned meaning" by judging their significance and value. Meaning cannot be separated from the person's past; it requires the thought of future and ultimately influences perception of that future.[11] Finding meaning is not a stagnant process; it changes as each day unfolds. As one patient reflected on his diagnosis, "Even though I have this I am still a whole person. My thoughts are different, my ambitions are a little different because I want to spend as much time as I can with my grand-kids."[12] Coming face to face with one's mortality not only clarifies what is important but also focuses the poignancy of the loss on much that has been meaningful.

One's spirituality is often the key to transcending those losses and finding ways to maintain those connections, whether it is the belief that one's love, work, or creativity will remain after the physical separation or the belief that one's spirit goes on to an afterlife. *Meaning in life* concerns the individual's realm of life on Earth. It has to do with one's humanness, the temporal, relationships, and what one

Table 36.1 Definitions of meaning

Meaning	"Refers to sense, or coherence. . . . A search for meaning implies a search for coherence. 'Purpose' refers to intention, aim, function. . . . however, 'purpose' of life and 'meaning' of life are used interchangeably"[5] "A structure which relates purposes to expectations so as to organise actions. . . . Meaning . . . makes sense of actions by providing reasons for it."[6]
[Search for] meaning	"An effort to understand the event: why it happened and what impact it has had . . . [and] attempts to answer the question(s), What is the significance of the event? . . . What caused the event to happen? . . . [and] What does my life mean now?"[7] "An attempt to restore the sense that one's life [is] orderly and purposeful."[8]
Personal search for meaning	"The process by which a person seeks to interpret a life circumstance. The search involves questioning the personal significance of a life circumstance, in order to give the experience purpose and to place it in the context of a person's total life pattern. The basis of the process is the interaction between meaning in and of life and involves the reworking and redefining of past meaning while looking for meaning in a current life circumstance."[9]

has done in life to give it meaning.[13,14] *Meaning of life* has more to do with the existential, beyond one's earthly physical existence to an eternal, secure, and indelible God or spiritual plane. The existential realm of life provides a sense of security whereby one can integrate experiences.[13,14]

Spirituality has been defined as a search for meaning.[15,16] One of the Hebrew words for meaning is *biynah* (bee-naw), understanding, knowledge, meaning, and wisdom. It comes from the root word *biyn* (bene), which means to separate mentally or to distinguish.[17] How does one come to knowledge and understanding? Patients who are dying often describe a sense of isolation and loneliness. They frequently have endless hours available while at the same time experiencing a shortening of their life. It is here that the nurse has a pivotal role as the listener, for when the ruminations of the dying are given voice, there is an opportunity for meaning. Important life themes are shared, and the unanswerable questions are asked. As a stranger, the nurse develops intimacy and trust with the patient, and meaning takes hold.

Suffering creates one of the greatest challenges to uncovering meaning. For the dying patient, suffering comes in many forms: physical pain, unrelenting symptoms, spiritual distress, dependency, multiple losses, and anticipatory grieving. Even the benefits of medical treatments given to provide hope or palliation can sometimes be outweighed by side effects, inducing yet further suffering. The dictionary defines *suffering*: "The condition of one who suffers; the bearing a pain or distress."[3] But once again, it is the root word that helps to move one—the Latin *sufferer*, which comprises *sub*, "below," and *ferre*, "to carry." The weight and isolation of suffering now becomes more real at the visceral level. Cassell[10] reminds us that pain itself does not foreordain suffering; it is the meaning that is attributed to that pain that determines the suffering. In his clinical definition, Cassell states: "Suffering is a state of severe distress induced by the loss of the intactness of person, or by a threat that the person believes will result in the loss of his or her intactness."[10(p. 63)] Clinicians can further unnecessary suffering, as attested to in the research by Berglund et al., by making patients feel objectified or by providing fragmented care.[18] Suffering is an individual and private experience and will be greatly influenced by the personality and character of the person; for example, the patient who has needed control during times of wellness will find the out-of-control experience of illness as suffering.[10] In writing about cancer pain and its meaning, Ersek and Ferrell[19] provide a summary of hypotheses and theses from the literature (Table 36.2).

It is the duty of all who care for patients to alleviate suffering and not just treat the physical dimensions of the illness. This is no small task, as professionals must first be free from denial and the need to

Table 36.2 Summary of hypotheses and theses from the literature on meaning

Hypothesis/thesis	Authors
The search for meaning is a basic human need.	Frankl 1959[4]
Meaning is necessary for human fulfillment.	Steeves and Kahn 1987[20]
Finding meaning fosters positive coping and increased hopefulness.	Ersek 1991[21]; Steeves and Kahn 1987[20]; Taylor 1983[8]
One type of meaning-making activity in response to threatening events is to develop causal attributions.	Gotay 1983[22]; Haberman 1987[23]; Steeves and Kahn 1987[20]; Taylor 1983[8]; Chrisman and Haberman 1977[24]
Meaning-making can involve the search for a higher order.	Ersek 1991[21]; Ferrell et al. 1993[25]; Steeves and Kahn 1987[20]
Meaning-making often involves the use of social comparisons.	Ferrell et al. 1993[25]; Taylor 1983[8]; Ersek 1991[21]; Haberman 1987[23]
Meaning can be derived through construing benefits from a negative experience.	Ersek 1991[21]; Haberman 1987[23]; Taylor 1983[8]
Meaning sometimes focuses on illness as challenge, enemy, or punishment.	Barkwell 1991[26]; Ersek 1991[21]; Lipowski 1970[27]
Pain and suffering often prompt a search for meaning.	Frankl 1959[4]; Steeves and Kahn 1987[20]; Taylor 1983[8]
Uncontrolled pain or overwhelming suffering hinder the experience of meaning.	Steeves and Kahn 1987[20]
One goal of care is to promote patients' and caregivers' search for and experiences of meaning.	Ersek 1991[21]; Ferrell et al. 1993[25]; Steeves and Kahn 1987[20]; Haberman 1988[28]

self-protect to see the suffering of another. Then, they must be able to attend to it without trying to fix it or simplify it. The suffering needs to be witnessed; in the midst of suffering, presence and compassion become the balm and hope for its relief.

The Process of Finding Meaning in Illness

Nurses who have worked with terminally ill patients and their families have found that many themes arise as a patient seeks meaning. The title given to each theme is an attempt to represent observed transitions that many terminally ill patients seem to experience. Not all patients move through the transitions in the same order, and not all transitions occur for each patient. The themes shared in this section are the imposed transition, loss and confusion, dark night of the soul, randomness and absence of God, brokenness, and reappraisal. In experiencing some or all of these transitions, patients may find meaning in this difficult time of life.

The Imposed Transition

When one is told that he or she has a terminal illness, it can be like hearing the sound of prison doors slam shut. Life will never be the same. The sentence has been handed down, and there is no reversing the verdict. For many, terminal illness is a loss, and there is nothing that can be done to change the prognosis even though the final outcome may temporarily be delayed. For some patients, the essence of their being is shaken, and their soul is stricken with a panic unlike any other ever felt. For the first time, they may be faced with an "existential awareness of nonbeing."[29] For a brief moment, the silence is deafening, as if suspended between two worlds, the known and the unknown. As the patient "regains consciousness," so to speak, the pain and pandemonium of thoughts and emotions may begin to storm the floodgates of their faith, coping abilities, and internal fortitude, while simultaneously the word "terminal" reverberates in one's head. For many, there is no easy or quick transition into the acceptance of a terminal diagnosis. Although there are circumstances where patients, either because of being so burdened by illness or frailty, may welcome dying.

For many patients, facing the end of life provokes questions. The self-reflective questions include both the meaning *of* life and the meaning *in* life. Whether one embraces with greater fervor the people and values that collectively give one meaning in life or one views it as now lost, the loss and pain are real. Nothing can be done to prevent the inevitable. There is a sense of separation or disconnectedness in the sense that while one remains the same person, he or she also becomes permanently different from others. In a rhetorical sense, the meanings one gains in life from relationships and the material world serve to affirm one as a participant in these meanings.[29,30] When these meanings are threatened by a terminal diagnosis, people may fear the loss of who they are as functioning productive and relational human beings. The affirmations they received from their meanings in life are now at a standstill.

Case Study: A Patient Who Wishes to Leave a Legacy

Accepting of his prognosis and not afraid of dying, an 84-year-old retired carpenter was not yet ready to die. He absolutely adored his grandchildren and they gave him great meaning in life. Life was always better when they were around. He was presently on his third line of chemotherapy for lung cancer, hoping it would allow him more time. He wanted his grandchildren to remember him and to know how much they meant to him.[31] When asked about leaving a legacy, he had not thought about it but was very interested. Several ideas were discussed, and he decided to write letters to each grandchild. The letters contained the same short biography of his life followed by personalized stories for each one from their childhood into adulthood. He commented on their strengths and ended with words of encouragement for the future. Each grandchild received his or her letter upon his death.

In addition to questioning meaning *in* life, many facing the end of life also question the meaning *of* life. A life-threatening illness makes it difficult to maintain an illusion of immortality.[32] "What happens when I die?" "Is there really a God?" "Is it too late for reconciliation?" For those believing in life after death, the questions may focus on the uncertainty of eternal life or the possibility of this being a test of faith. No matter what the belief system, the existential questions are asked.[33] Many may reach out for a connection with God or something beyond one's self to obtain some sense of security and stability. Then, in this ability to transcend the situation, ironically, one may feel a sense of groundedness. Frankl[4] states, "It denotes the fact that being human always points, and is directed, to something or someone, other than oneself—be it a meaning to fulfill or another human being to encounter." There is a strong spiritual need to find meaning in this new senseless and chaotic world. Ellingsen et al. interviewed terminally ill patients and explored this concept of being in "transit" as being experienced by both time and space. The vulnerability of an incurable illness and the state of embodied suffering can be altered by the establishment of a safe environment (i.e., pain skillfully addressed), which in turn diminished the unpredictable aspects of the body's failure. This creation of predictability, safety, and also a sense of home allowed for a transition with a feeling of security and peacefulness.[34]

Loss and Confusion

One cancer patient stated, "Our lives are like big run-on sentences and when cancer occurs, it's like a period was placed at the end of the sentence. In reality, we all have a period at the end of the sentence, but we don't really pay attention to it."[35] With a terminal diagnosis, one may feel as if life is changed forever, for however long that life may be. Each day, life seems to change as one is forced to experience a new aspect of the loss.[36–38] There is a sense of immortality that pervades one's lust for life, and when made to look at one's mortality, it can be staggering. With all of the many losses, coupled with the fear of dying, one may feel confused from the infinite possibilities of the unknown. The panorama of suffering, at times, seems to be limitless.

For many, the pain of loss is as great as the pleasure derived from life.[39] Confusion is caused not only from one's world having been turned upside down; it is also caused by those who love us and care about us. It is not intentional; nevertheless, its impact is greatly felt. In trying to encourage or trying to help find meaning, friends and family may unintentionally minimize the loss and pain by comparing losses, by denying the freedom to be angry at God, or by immediately focusing on the time left to live. The hurting soul needs to feel the depth of the loss by whatever means it can. The pain from loss can be relentless.

Case Study: A Patient Confronting Mortality

A 46-year-old woman with advanced renal cancer stopped her treatment due to illness progression. Additional long-standing comorbidities had greatly limited her physical activities, exposing her to many losses over the years. She knew she was going to die and wanted to talk about it with her family. Thinking they were acting in her best interest, the family would not engage the patient on this topic believing that it would be too much of a burden. This was both frustrating and hurtful to her. What the family did not realize was that this refusal to engage imposed yet another loss for her. Their approach, as loving as they were trying to be, only served to remind her of her impending death.

In Tolstoy's *The Death of Ivan Ilyich*, one hears the agony of Ivan's similar experience, "This deception tortured him—their not wishing to admit what they all knew and what he knew, but wanting to lie to him concerning his terrible condition, and wishing and forcing him to participate in that lie. . . . And strangely enough, many times when they were going through their antics over him he had been within a hairbreadth of calling out to them: 'Stop lying! You know and I know that I am dying. Then at least stop lying about it!' But he had never had the spirit to do it."[40(p. 86)]

Dark Night of the Soul

There are patients who go through a period of the extraordinary work of the dark night of the soul. As difficult as this work is, it holds promise of transformation. The descent into darkness pervades every crack and crevice of one's being. One now exists in the place of Nowhere surrounded by nothingness that is void of texture and contour. One's signature is seemingly wiped away, taking with it the identification of a living soul.[39] Job states, "My days are swifter than a weaver's shuttle, and come to an end without hope . . . my soul is poured out within me; days of affliction have seized me. At night it pierces my bones within me, and my gnawing pains take no rest . . . ."[41] "One enters the abyss of emptiness—with the perverse twist that one is not empty of the tortured feeling of emptiness."[42] This is pain's infinite desert.

For some, darkness looms as one thinks about the past, full of people and things that provided meaning in life that will soon have to be given up. Darkness looms as one thinks about the future because death precludes holding on to all that is loved and valued. Darkness consumes one's mind and heart like fire consumes wood. It makes its way to the center with great fury, where it proceeds to take possession, leaving nothing but a smoldering heap of ashes and no hope of recovering any essence of life.[43]

Case Study: A Patient Struggling with Darkness

After several years free of ovarian cancer, a 33-year-old woman was informed that the cancer had recurred. Her first thoughts were of her three girls, ages 7, 9, and 12. She opted to go on a clinical trial, hoping to gain more time. After only 6 months, the cancer progressed. She became depressed and agonized over leaving her girls at such critical ages. She tormented herself thinking about whether she had done the right thing in pursuing the clinical trial. Her children would lose her anyway, what had she accomplished except time away from them? She experienced an inconsolable darkness and needed help. The nurse was present to her suffering, allowing her space to grieve. They worked together on a plan for the patient to focus on being a mother as well as preparing the girls for her death. The patient was able to move through the darkness and into meaning.

Although one might try, there are no answers—theological or otherwise—to the "whys" that engulf one's existence. Death moves from an "existential phenomenon to a personal reality."[44] For many, presuppositions about life fall away, and one is left emotionally naked. In the dark night of the soul, there is neither the physical, the emotional, nor the spiritual strength to help one's own fragility. The world becomes too big, and one's inner world is overwhelming.[39] The enigma of facing death strips order from one's life, creating fragmentation and leaving one with the awareness that life is no longer tenable. This is a time when patients are at risk for considering physician-assisted suicide and need careful assessment and support.

Randomness and the Absence of God

For many, the pronouncement of a terminal diagnosis may provoke inner turmoil and ruminating thoughts from dawn to dusk. Even in one's chaotic life, there was order. But order does not always prevail. A policeman is killed responding to a domestic violence call. A young man is struck and killed by lightning while in his home. Children are held hostage and abused by their parents. Hurricanes devastate cities, killing hundreds. There seems to be no reason. It would be different if negligence were involved. For example, if the young man was walking outside during a thunderstorm; although the loss is still quite devastating, a "logical" reason could be assigned to it. But randomness leaves us with no "logical" explanation.[42]

The word "random" comes from the Middle English word *radon*, which is derived from the Old French word *randon*, meaning violence and speed. The word connotes an impetuous and haphazard movement, lacking careful choice, aim, or purpose.[3] The feeling of vulnerability is overwhelming. In an effort to find shelter from this randomness, many may seek meaning and comfort from God or from something beyond one's self, but how does one know that God or something beyond one's self is not the cause of one's loss? One's trust may be shaken. Can one reconcile God's sovereignty with one's loss?[42] Can one stay connected to and continue to pull or gain strength and security from something beyond one's self that may be the originator of one's pain? There is a sense of abandonment by that which has been one's stronghold in life. Yet to cut one's self off from that stronghold out of anger would leave one in a state of total disconnection. A sense of connection is a vital emotion necessary for existence, no matter how short that existence may be. But facing death forbids one to keep one's existential questions and desires at a distance. Rather, it seems to propel one into a deeper search for meaning as the questions continue to echo in one's mind.

Brokenness

Does one come to a place of acceptance within brokenness? Is acceptance even attainable? Sometimes. Sometimes not. Coming to a place of acceptance is an individual experience for each person. In a wonderful analogy of acceptance, Kearney states, "Acceptance is not something an individual can choose at will. It is not like some light switch that can at will be flicked on or off. Deep emotional acceptance is like the settling of a cloud of silt in a troubled pool.

With time the silt rests on the bottom and the water is clear."[45 (p. 98)] Brokenness does, however, open the door to relinquishing the illusion of immortality. Brokenness allows the soul to cry and to shed tears of anguish. It elicits the existential question "Why?" once again, only this time not to gain answers but to find meaning.

Case Study: A Patient Finding Meaning

When younger, knitting had always been a way for this 67-year-old woman to relax. Over the years of raising children and volunteering with the local Rotary Club, she found that knitting went by the wayside. Diagnosed with advanced breast cancer 6 months ago, the woman's cancer continued to progress in spite of treatment. No longer able to ambulate even with a walker, she was confined to the hospital bed in her home. At first, she was angry at God, sad, and resentful of having to live this way. Reminiscing with her granddaughter during a recent visit, they talked about her knitting days. Inspired by her granddaughter's encouragement, she decided to start knitting again. This activity gave her peace as well as a purpose. Before she died, she had knitted an animal for each child in her granddaughter's first-grade class.

If we go back to the poem at the beginning of this chapter, it wasn't until "sanity" was lost that the rose was found. A gradual perception occurs, whereby one realizes that the way out is by no longer struggling.[45] When one comes to the end of one's self and the need to fight the inevitable that is death, space is given for meaning to unfold. It is not that one gives up the desire but that one relinquishes the need to emotionally turn the situation around and to have all questions answered. Sittser, a minister who experienced a sudden loss of several immediate family members, stated, "My experience taught me that loss reduces people to a state of almost total brokenness and vulnerability. I did not simply feel raw pain; I was raw pain."[42(p. 164)] Pain and loss are still profound, but in the midst of these heavy emotions there begins to be a glimmer of light. Like the flame of a candle, the light may wax and wane. It is enough to begin to silhouette those people and things that still can provide meaning.

Reappraisal

It is here where one begins to realize that something positive can come from even a terminal diagnosis and the losses it imposes.[46,47] The good that is gained does not mitigate the pain of loss but rather, it fosters hope—hope that is not contingent on healing but on reconciliation, on creating memories with loved ones, on making the most of every day, on loving and being loved.[48] It is a hope that transcends science and explanations and changes with the situation. It is not based on a particular outcome but, instead, focuses on the future, however long that may be. Despair undermines hope, but hope robs death of despair.[49]

Case Study: A Patient Finding Hope

After a 15-year remission, a male patient in his mid-40s diagnosed with a relapse of leukemia, required a bone marrow transplant. He spent a long time in the hospital, including 35 days in isolation. Once moved to a regular room and allowed to leave his room, he visited a young teenage girl down the hall who was struggling with treatment side effects and ready to give up. They became friends, and, when possible, he would sit with her during part of her treatment and they would talk or just be quiet. Through this personal interchange, they strengthened each other's hope.

Encountering a terminal diagnosis is complex and challenging. It will always have tragic aspects because it causes pain and loss to everyone involved.[50,51] But, at a time unique to each person facing death, a choice can be made as to whether one wants to become bitter and devalue the remaining time or value the time that is left as much as possible.

An important choice to be made during this time is whether to forgive or to be unforgiving—toward oneself, others, God, or one's stronghold of security in life.[52] Being unforgiving may breed bitterness and superficiality. As one faces the end of life, one needs both an existential connection and a connection with others. Being unforgiving can separate one from those connections, and it is only through forgiveness that the breach is healed. Forgiveness neither condones another's actions nor does it mean that this terminal diagnosis is fair. Rather, forgiveness is letting go of expectations that one somehow will be vindicated for the pain and loss. Whether by overt anger or by emotional withdrawal, in seeking to avoid vulnerability to further pain and loss, one only succeeds in making one's self more vulnerable. Now one has chosen a deeper separation that goes beyond facing the death of the physical body—that of the soul.[42] Vulnerability through forgiveness provides a means of healing and, when possible, reconciliation with others. It provides healing and reconciliation with one's God or one's stronghold of security. Forgiveness allows both physical and emotional energy to be used for creating and enjoying the time left for living.

Case Study: A Patient in Need of Forgiveness

A 28-year-old woman was admitted to the hospital with advanced colon cancer. She was single, a business woman, and close with her sister and father. During the intake, she stated that her mother was deceased. When offered standard supportive care, she refused social work and chaplaincy. She felt like she had everything under control even though she had been seen crying when she thought no one was watching. While in her room, a nurse was able to engage her in conversation. The nurse learned that the patient's mother was not dead, rather, she was a psychiatric patient who had left her, her younger sister, and their father when the girls were little. Her mother refused help for years and when she finally sought help, was noncompliant with appointments and medications. She called her daughters out of the blue, sometimes crying and other times not making any sense. The patient kept her mother out of her life and did not want her at the hospital. As far as she was concerned, her mother's actions were unforgiveable. Over time, through presence and gentle conversation, the nurse encouraged the patient to open up in an environment of emotional safety. This time a chaplaincy offer was accepted. One may not always be able to fix the pain of life's fractures or bring people to a place of forgiveness, but it is important not to underestimate what is happening in the moment.

There are many emotions and issues with which those facing death must contend. It is not an easy journey, and the process is wearing; nevertheless, the rose can be found.

Impact of the Terminal Illness on the Patient–Caregiver Relationship

Each person comes to new situations with unique life experiences and the meanings gained from them. It is no different when confronted with illness and the end of life. However, in this special episode of life, there are often no personal "reruns" from which to glean insight. Patient and family come together as novices, each helping the other through this unknown passage.[53] Because different roles and relationships exist, the impending loss will create different meanings for each person involved.

Facing the loss of someone you love is extremely difficult. For the family caregiver, the process of finding meaning is influenced by the one facing death. One example involved a wife's discussion with her terminally ill husband over several months regarding his outlook on life. As Christians, they knew death would take them to heaven, but she was curious as to what that meant to him and how he was handling the unknown. She felt strong in her own faith but also felt like she was giving lip service to it at times. He described life as having even more meaning in that, although he loved her very much and the life they had together, he could now "cherish" every moment of that time. He was sad knowing that he would eventually die from the cancer, but until that time came, he just wanted to enjoy life with her. She shared that while what he said seemed obvious when he said it, for some reason, this time it really spoke to her soul and she felt peace.

In another example, a female patient with renal cancer wanted to help her family create meaning as they went through the cancer journey with her. She bought each of her four adult children a photo scrapbook and asked them to spend a weekend with her but did not explain why. When they arrived, the patient had pictures, letters, drawings, and other memorabilia, ready for them to create their own meaningful memories. There were lots of tears and laughter. The patient died just 2 weeks later.

One final story. A 45-year-old woman was a heart transplant recipient 2 years before being diagnosed with stage IV lung cancer. Her shortness of breath had increased, which both frustrated and scared her. She was very active in community arts as well as in raising horses, and she already had cut back on the community arts. She was a strong woman who didn't want to need help, and she was supported by a loving husband of many years. She was depressed and refused any medication. She struggled greatly with anger and resentment at having had a life-saving heart transplant only to get cancer. Life was fast losing meaning for her. She received several lines of chemotherapy but each one worked only a short time before the cancer progressed. Her main goal now was to live long enough to see the foal that would be born soon. On her last visit to the hospital before starting hospice, a friend who had visited the farm encouraged her to stop and visit the foal that was born the day before in case she was unable to leave the house again. The husband and wife did just that. Seeing the foal meant the world to her, and she died peacefully at home several days later.

These actual patient stories were presented to exemplify how the patient's meaning in illness affects the meaning held or created by family members. Differing or divergent meanings can be detrimental in a relationship, or they can be used to strengthen it, thereby increasing the quality of time left together. That is not to imply that the patient is responsible for the meaning created by family members; rather, they are responsible for how one affects the other. Germino, Fife, and Funk[54] suggest that the goal is not merely arriving at a single meaning within the patient–family dyad but, rather, encouraging a sharing of individual meanings so that all can learn and relationships can be deepened and strengthened.

There are many issues that family caregivers face in caring for a loved one nearing the end of life.[55–57] There is one issue, however, that warrants more attention: the loss of dreams—the loss of dreams for a future with a loved one, in addition to the loss of the person him- or herself. It is the loss of the way one used to imagine life and how it would have been with that person. It is the loss of an emotional image of oneself and the abandonment of chosen plans for the future and what might have been.[58]

For a child and the surviving parent, those losses of dreams will be played out each time Mother's or Father's Day arrives and at important life-cycle events, such as graduations, weddings, or the birth of the first grandchild. As her mother lay dying, one child expressed that loss in the simple statement, "Mommy, you won't be here for my birthday!" The mother and child wept, holding and comforting each other. Nothing could change the loss, but the comfort of love would remain forever.

The loss of dreams is an internal process, spiritual for some, and seldom recognized by others as needing processing.[35,58–60] Nurses have a wonderful opportunity to verbally acknowledge the family caregivers' loss of dreams and to encourage them in their search to find meaning in the loss. The ability to transcend and connect to God or something greater than one's self helps the healing process.

Transcendence: Strength for the Journey that Lies Ahead

Transcendence is defined as lying beyond the ordinary range of perception; being above and independent of the material universe. The Latin root is *trans-*, "from or beyond," plus *scandere*, "to climb."[3] The images are many: the man in a pit climbing his way out one handhold at a time; the story of the Biblical figure Job as he endured one loss after another and yet found meaning; the climber who reaches the mountaintop, becoming closer to the heavens while still having the connection to the earth; or the dying patient who, in peace, is already seeing into another reality. The ability to transcend truly is a gift of the human spirit and often comes after a long struggle and out of suffering. It is often unclear which comes first—does meaning open the door for transcendence, or, quite the opposite, does the act of transcendence bring the meaning? More than likely, it is an intimate dance between the two, one fueling the other. In the Buddhist tradition, suffering and being are a totality, and integrating suffering in this light becomes an act of transcendence.[61]

Transcendence of suffering can also be accomplished by viewing it as reparation for sins while still living—preparing the way for eternity, as in the Islamic tradition. In other traditions, transcendence is often relationship-based, involving the connection to others and sometimes to a higher power.[4] For example, the Christian seeing Christ on the cross connects one to the relationship and endurance of God and the reality that suffering is a part of life. For others, it is finding meaning in relating to and caring for others. And for some, that relationship may be with the Earth, a sense of stewardship and leaving the environment a better place. It is rare that patients reach a state of transcendence and remain there through their dying. Instead, for most, it is a process in which there are moments when they reach a sense of expansion that supports them in facing death. The existential crisis does not rule because one can frame the relationship beyond death; for example, "I will remain in their hearts and memories forever, I will live on through my children, or my spirit will live beyond my limited physical state."

Nursing Interventions

If one returns to the root word of "meaning," *maenan*, or "to tell of," this concept can be the guide that directs the nurse toward interventions. Given the nature of this work, interventions may not be the true representation of what is needed. Intervention implies action—that the nurse has an answer, and she or he can direct the course of care by intervening. "Intervention" is defined as "To come, appear, or lie between two things. To come in or between so as to hinder or alter an action."[3] But finding meaning is process-oriented; while finely honed psychosocial skills and knowledge can be immensely helpful, there is no bag of tricks. One example would be of a chaplain who walks into the room and relies only on offering prayer to the patient, preventing any real discourse or relationship-building. The patient's personhood has been diminished, and, potentially, more harm than good has been done.

In revisiting *maenan* "to tell of," then, what is required of the professional who enters into the healing dimension of a patient's suffering and search for meaning?[62] Respect may be the starting point—respect for that individual's way of experiencing suffering and attempts of making sense of the illness. Second, allow for an environment and time for the telling.[63,64] Even as this is read, the sighs of frustration are heard, "We have no time!" If nursing fails at this, if nurses turn their backs on their intrinsic promise to alleviate suffering, then nursing can no longer exist. Instead, the nurse becomes simply the technician and the scheduler—the nurse becomes a part of the problem. She or he has violated the American Nurses Association's Code of Ethics for Nurses that asserts that they are obligated to address the alleviation of suffering and provide supportive care to the dying: "Optimal nursing care enables the patient to live with as much physical, emotional, social, and spiritual well-being as possible and reflects the patient's own values. Supportive care is particularly important at the end of life in order to prevent and alleviate the cascade of symptoms and suffering that are commonly associated with dying."[65(p. 1)]

If patients in the midst of suffering receive the message, nonverbally or directly, that there is no time, energy, or compassion, they will, in their vulnerability, withdraw or become more needy. When patients feel distrusted, objectified, and overlooked, they suffer at the hands of those who were to provide care.[18] Their alienation may become complete. On the other hand, if privacy and a moment of honor and focused attention are provided, this allows for the tears to spill or the anguish to be spoken. Then the alienation may be eliminated, and the opportunity for healing is begun.

The terminally ill are a vulnerable population. They die and do not complete patient satisfaction surveys; their grievances and their stories die with them. But any violation or neglect does not stop, for each nurse now holds that violation, as does society as a whole. The wound begets wounds, and the nurse sinks further into a guarded and unavailable approach, alienated. Without engagement or connection, the work holds few rewards, only endless days and demands. She or he has nothing left to give. The patient and family are ultimately abandoned. In the work of Kahn and Steeves,[66] one finds a model for the nurse's role in psychosocial processes and suffering. It represents the dynamic relationship of caring, acted out in caregiving as well as in the patient's coping, which transform each other.

For the nurse to provide this level of caregiving, he or she must understand the obstructions that may interfere. It is essential that the nurse undergo his or her own journey, visiting the intense emotions around the dying process and the act of witnessing suffering. A nurse can serve the suffering person best when she or he is willing to be transformed through the process of one's own grief as well as by the grief of others.[67]

In light of pervading technology, nurses need to be careful that technology does not enable them to avoid, even if inadvertently, being present with their patients.[68,69] Presence may, in fact, be the greatest gift to these patients and their families. Still, imagine charting or accounting for presence on an acuity system! Presence "transcends role obligations and acknowledges the vulnerable humanness of all . . . to be present means to unconceal, to be aware of tone of voice, eye contact, affect, and body language, to be in tune with the patient's messages."[67] Presence provides confirmation, nurturing, and compassion and is an essential transcendent act.

Touch becomes one of the tools of presence and is valued by the dying and their families.[70,71] It has also been shown to reduce anxiety, pain, and fatigue in adults as well as children.[72–74] Used with sensitivity and respect, touch can be as simple as the holding of the hand or as powerful as the holding of the whole person. Sometimes, because of agitation or pain, direct touch becomes intrusive; even then touch can be invoked, by the touching of a pillow or the sheet or the offering of a cold cloth.

Listening is more than the collection of data; it is therapeutic in providing space for the narrative to take place.[75–77] If a key aspect of meaning is to tell, then one might be led to believe that the spoken word would be imperative. However, over and over, it is silence that conveys the meaning of suffering, "a primitive form of existence that is without an effective voice and imprisoned in silence." Compassionate listeners in respect and presence silence their voice, open their heart, and share the stillness.[67,78] They use the most intuitive skills to carry the message. This may also be why other approaches that use symbols, metaphors, and the arts are the most potent in helping the patient communicate and make sense of meaning. The arts, whether writing, music, or visual arts, often help the patient not only gain new insight but also convey that meaning to others. There are many levels on which this is accomplished. Whether it is done passively through reading poetry, listening to music, or viewing paintings, or actively through creation, thoughts can be inspired, feelings moved, and the sense of connectedness and being understood can evolve.[63,69,79,80] What once was ubiquitous can now be seen outside of one's soul, as feelings become tangible. It can be relational because the act of creation can link one to the creator, or it can downplay the role of dependency, as the ill one now cares for others with a legacy of creational gifts.[79]

Meditation, mindfulness, and yoga are other acts of transcendence that can be extremely powerful for the dying.[63,81–85] Even those who have never experienced a meditational state can find that this new world in many ways links them to living and dying. The relaxation response from meditation or yoga allows the anxious patient to escape into a meditative state, experiencing an element of control while relinquishing control. Many patients describe it as a floating state, a time of great peace and calm. Some who have never had such an experience can find the first time frightening as the existential crisis, quelled so well by boundaries, is no longer confined. Most, given a trusting and safe teacher, will find that meditation will serve them well. The meditation can be in the form of prayer, guided imagery, breathing techniques, or mantras.

Prayer is well-documented in the literature[86–90]as having meaning for patients and families; not only does it connect one to God, but it also again becomes a relational connection to others. Knowing that one is prayed for not only by those close at hand but by strangers, communities, and those at a great distance can be deeply nurturing. Often forgotten is the role in which the patient can be empowered: that of praying for others. One patient prayed for her nurse and her nurse's healing, and, in so doing, the patient lost the sense of worthlessness and glowed with joy.

Leaving a legacy may be one of the most concrete ways for patients to find meaning in this last stage of their lives.[91–93] It most often requires the mastering of the existential challenges, in which patients know that death is at hand and choose to direct their course and what they leave behind. For some patients, that will mean going out as warriors, fighting until the end; for others, it will mean end-of-life planning that focuses on quality of life. Some patients will design their funerals, using rituals and readings that reveal their values and messages for others. Others will create videos, write letters, or distribute their wealth in meaningful ways. Dignity therapy, life review, and legacy documents are interventions being utilized successfully with the dying.[94,95] Blogging is a way to decrease a sense of isolation for patients as they record their experiences and also leaves a permanent imprint of their lives on the Internet.[96–100] It becomes a diary of the illness and has been shown to increase a sense of purpose and meaning as they share with others.[96,101–103] Vlogging (video blog) is another way for patients to share their cancer experiences as well as a means for leaving a legacy.[104,105] Parents who are leaving young children sometimes have the greatest difficulty with this aspect. On one hand, the feelings of horror at "abandoning" their children are so strong that they have great difficulty facing their death. Still, there is often a part of them that has this need to leave a legacy. The tug-of-war between these two willful emotions tends to leave only short windows of opportunity to prepare. The extreme can be observed in the mother who slowly pushed her teenage daughter away, using excuses for the distancing. It was only after a trusting relationship had been established with one of her nurses that helped her to see how this protective maneuver was, in fact, harming her daughter. The mother needed not only to see what she was doing but to see how her love would help her daughter and how others would be there for her and her husband in their pain and grief. With relief, the mother reconnected to her daughter, creating living memories and a lifetime protection of love.

Another courageous parent anticipating the missed birthdays, bought cards and wrote a note in each one, so that the child would be touched not only by the individual messages, but the knowledge that the parent found a way to be there for him with each new year. A mother wrote a note for her young daughter so that if she should ever marry, she would have a gift to be opened on her wedding day. The note described the mother's love, wisdom about marriage, and her daughter's specialness, already known through a mother's eyes. An elderly person may write or tape an autobiography or even record the family tree lest it be lost with the passing of a generation. The nurse can often be the one who inspires these acts, but it must always be done with great care, so as not to instill a sense of "should" or "must," which would add yet another burden.

Helping patients to reframe hope is another important intervention.[106–108] Dr. William Breitbart, chief of the Psychiatry Services at Memorial Sloan-Kettering Cancer Center in New York City, designed and conducted research on a meaning-centered psychotherapeutic intervention to help terminally ill patients with cancer maintain hope and meaning as they face the end of their lives.[5,109] This research was inspired by the works of Dr. Victor Frankl, a psychiatrist and Holocaust survivor. Cancer patients attended an 8-week, group-focused, standardized course of experiential exercises that addressed constructs of despair at the end of life, such as hopelessness, depression, loss of meaning, suicidal ideation, and desire for a hastened death. The study revealed that the patient's spiritual well-being and loss of meaning was more highly correlated to the components that made up despair at the end of life than either depression or hopelessness alone. As a result, if the patient could manipulate or reframe his or her sense of meaning and spiritual well-being, this would positively affect the foundational elements of despair at the end of life. When patients are able to do this, their hope may be sustained because they have been able to reframe the focus of their hope.

The Healthcare Professional

Although the healthcare professional can be educated about death and grieving, like the patient and family, it is in living out the experience that understanding is reached. It is a developmental process, and, given the demands of the work, the nurse is at great risk for turning away from her or his feelings. There is often little mentoring that accompanies the first deaths, let alone formal debriefing or counseling. How can it be that we leave such important learning to chance? And what about cumulative losses and the impact of the years of witnessing suffering? Healthcare needs healing rituals for all of its professionals to support and guide them in this work. Individual institutions can develop programs that address these needs.

At one institution, "Teas for the Soul" (sponsored by the Spiritual Care Department) provide respite in the workplace on a regular basis, as well as after difficult deaths or traumas. A cart with cookies and tea, as well as soft music, is provided as physical and emotional nurturance for the staff and to legitimize the need to come together in support. Another support is a renewal program, the "Circle of Caring." This retreat supports healthcare professionals from a variety of institutions in a weekend of self-care that integrates spirituality, the arts, and community-building. The element of suffering is a focal point for a small-group process that unburdens cumulative effects of the work and teaches skills and rituals for coping with the ongoing demands.

Perhaps one of the most challenging aspects of finding meaning for a nurse is when nonbeneficial treatment is continued and palliative care is forestalled. The nurse experiences not only the emotional burden of the normal emotions of caring for the dying, but now has the added weight and guilt of feeling that she or he is contributing to harming the patient. While efforts must be made to address the nonbeneficial treatment and refocus on appropriate goals of care, during that gap, it is essential that nurses and the entire healthcare team attend to the moral distress. Research has demonstrated that speaking up clearly makes a lasting impact on moral distress and yet often it is not addressed. The potential for elevation of the crescendo effect is significant, as is detaching from patients or even leaving the profession.[110–112] Ultimately, even if constrained by a lack of do-not-resuscitate orders or continued burdensome treatments, the nurse can focus her or his intentions on what she or he is able to do for the patient and family. Whether it is treating the patient with respect and tenderness or humanizing the experience through the simplest of acts (offering music, the reading of a poem, or comfort to those at the bedside), an awareness of the moral action of caring, so essential to nursing, will not only improve the care but the resiliency of the nurse.

Clearly, there is much that can be done to support nurses individually and to support organizations. There are many opportunities for assisting nurses in their own search for meaning and for enhancing the care of patients and families. When the nurse takes the time to find meaning in this work, she or he is finding a restorative practice that will protect him or her personally and professionally. "Searching for and reflecting on meaning becomes the wellspring that helps balance the draining aspects of caring work, and perhaps even more importantly, is a constant reminder of the richness of a life well lived."[113] Like the patient, she or he will need to choose this journey and find pathways that foster, challenge, and renew.

> As long as we can love each other,
> And remember the feeling of love we had,
> We can die without ever really going away.
> All the love you created is still there.
> All the memories are still there.
> You live on—in the hearts of everyone you have
> Touched and nurtured while you were here.
>
> —*Morrie Schwartz*[114(p. 174)]

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SECTION IV

Special Patient Populations

CHAPTER 37

Cultural Considerations in Palliative Care

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Key Points

- Quality palliative care requires consideration of patient and family cultural values, practices, and beliefs.
- A multidimensional assessment of an individual's and family's culture is essential to providing quality palliative care.
- An individual's culture encompasses multiple components, including race, ethnicity, age, gender, socioeconomic status, differing abilities, sexual orientation, religion, and spirituality.
- Cultural self-awareness is necessary if nurses are to better understand their own values, practices, and beliefs and the impact these may have on the care of others.

Culture Defined

Culture is "the integrated pattern of human knowledge, belief, and behavior that depends upon the capacity for learning and transmitting knowledge to succeeding generations."[1] Shaped over time, these beliefs, traits, values, and lifestyle patterns are designed to ensure survival and well-being and to find a common purpose or meaning throughout life.[2]

Although culture is often mistakenly thought of as simply race and ethnicity, the definition of culture is multidimensional, encompassing such components as age, gender, languages, religion and spirituality, socioeconomic class, differing abilities, composition of family, and geographic environment.[3] Each cultural component plays a role in shaping individual responses throughout one's entire life span, from birth until time of death.[2,3]

A broad definition of culture recognizes that various *subcultures* exist within the dominant cultures. These subcultures may further affect individuals' experiences and responses in any given situation, including dealing with trauma or serious illness and end of life. It is essential that nurses consider the role that culture or subcultures may play in patient and family choice and decision-making during these more difficult times. The nurse must also be constantly aware that the culture of the healthcare system and the culture of the nursing profession, as well as his or her own personal beliefs, may shape the interactions with patients, families, and colleagues.

Culture as a Global Palliative Care Issue

Care of the seriously ill and dying is complex, with many of these individuals coping with multiple chronic illnesses, age-related syndromes and needs, complicated medication regimens aimed at ameliorating symptoms of disease, and often a limited social support and caregiver base to help with care. Globally, nurses need to acquire and maintain generalist palliative care nursing knowledge and skill to address the unique needs of individuals coping with serious illness and their families. Variations in global nursing education and workforce challenges exist, yet attention to the cultural aspects of care, regardless of where one lives, is necessary to providing compassionate and skilled nursing care across disease states. Discussion of all cultural variations is beyond the scope of this chapter; however, the authors encourage readers to consider how to apply key concepts to their specific global setting.[4]

Increasing Diversity in the United States

As the United States becomes increasingly diverse, the growing range of treasured beliefs, shared teachings, norms, customs, and languages challenges the nurse to understand and respond to a wide variety of perspectives. The total US population in 2016 was estimated to be 323.1 million.[5] Population statistics from the US Census Bureau illustrate that cultural diversity is increasing among the five most common pan-ethnic groups, which are federally defined as American Indian/Alaska Native, Asian/Pacific Islander, black or African American, Hispanic, and white (Table 37.1).[6]

Census projections suggest that, by 2060, the combined minority groups that currently make up 37% of the US population will constitute the majority (57%).[6] Globally, the population aged older than 60 is expected to more than double in the next several decades from 841 million in 2013 to more than 2 billion in 2050,[7] and the number of the "oldest old," the 85 and older age group, is expected to more than triple. This trend will present significant challenges to health systems and healthcare providers worldwide as they look to meeting the needs of older adults.[4]

With these changes in cultural diversity comes increasing diversity in the nursing workforce. Beliefs and attitudes about nursing's role and the status of the nurse may be underappreciated or not acknowledged in some parts of the world. Nurses must be aware of how their own cultural beliefs and norms shape their professional

Table 37.1 US ethnic group census estimates for 2017

White alone	76.9%
White alone, non-Hispanic or Latino	61.3%
Hispanic or Latino alone	17.8%
Black or African American alone	13.3%
Asian alone	5.7%
American Indian/Alaska Native alone	1.3%
Hawaiian and Other Pacific Islanders	0.2%

Source: https://www.census.gov/quickfacts/fact/table/US/PST045216

practice and differ from the beliefs and norms of the patients and families for whom they care.

Culture and Palliative Care Nursing

The essence of palliative nursing is to provide holistic supportive care for the patient and the family living with a serious or life-limiting illness. Palliative nursing strives to meet the physical, emotional, social, and spiritual needs of the patient and family across the disease trajectory.[8] To meet these needs, nurses must recognize the vital role that culture has on one's experience of living and dying. The beliefs, norms, and practices of an individual's cultural heritage guide one's behavioral responses, decision-making, and actions.[3] Culture shapes how an individual makes meaning out of illness, suffering, and death.[9] Nurses, along with other members of the interdisciplinary team, partner with the patient and family to ensure that patient and family values, beliefs, and practices guide the plan of care.[10]

The National Consensus Project (NCP) *Clinical Practice Guidelines for Quality Palliative Care*[11] define the core concepts and structures for quality palliative care delivery. The guidelines comprise eight domains with corresponding criteria that reflect the depth and breadth of the specialty. Cultural aspects of care constitute one of the eight domains, emphasizing the central role that culture plays in providing strength and meaning for patients and families facing serious illness.[11] Within this domain, two overarching guidelines define culture and outline cultural competencies for interdisciplinary team members (Box 37.1).

Culture is a source of resilience for patients and families and plays an important role in the provision of palliative care. It is the responsibility of all members of the palliative care program to strive for cultural and linguistic competence to ensure that appropriate and relevant services are provided to patients and families. The following case illustrates the challenges faced when caring for a patient and family with serious illness and importance of cultural considerations.

Box 37.1 *Clinical Practice Guidelines for Quality Palliative Care*: Cultural Aspects of Care

Guideline 6.1 The palliative care program serves each patient, family, and community in a culturally and linguistically appropriate manner.

Criteria:

- Definition of culture and cultural components
- Cultural identification of patient/family
- Assessment and documentation of cultural aspects of care
- The plan of care addresses the patient's and family's cultural concerns and needs
- Respect for the patient's/family's cultural perceptions, preferences, and practices
- Palliative care program staff communicate in a language and manner that the patient and family understand and take into account
    - Literacy;
    - Use of professional interpreter services and acceptable alternatives;
    - Written materials that facilitate patient/family understanding.
- Respects and accommodates dietary and ritual practices of patients/families
- Palliative care staff members identify and refer patients/families to community resources as appropriate.

Guideline 6.2 The palliative care program strives to enhance its cultural and linguistic competence.

Criteria:

- Definition of cultural competence.
- Valuing diversity in the work environment. Hiring practices of the palliative care program reflect the cultural and linguistic diversity of the community it serves.
- Palliative care staff cultivate cultural self-awareness and recognize how their own cultural values, beliefs, biases, and practices inform their perceptions of patients, families, and colleagues.
- Provision of education to help staff members increase their cross-cultural knowledge and skills and reduce health disparities.
- The palliative care program regularly evaluates and, if needed, modifies services, policies, and procedures to maximize its cultural and linguistic accessibility and responsiveness. Input from patients, families, and community stakeholders is integrated into this process.

Source: Adapted from National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care* 2013. www.nationalconsensusproject.org.

Case Study: Cultural Considerations of a Family

Cristina, a 17-year-old girl, had a long medical history of tuberous sclerosis, a complex, genetic condition that causes tumors in the brain and other vital organs. Cristina was nonambulatory, nonverbal, and fully dependent on others for all of her needs. She lived in a trailer with her father and mother. Her primary caretaker was her mother, Rosa, who was 39 years old. Rosa did not speak English. She came to the United States from Mexico at 24 years of age, in hopes of a better life and better medical care for herself and her daughter. Rosa also had tuberous sclerosis, although less severe, and complications included tumors in her lungs. Her disease had progressed over the past few years and she was dependent on oxygen and unable to lift Cristina independently. A lung transplant had been recommended for Rosa, but due to her immigration status she was ineligible for health insurance. Her only hope for curative medical treatment was to return to Mexico, but the logistics of getting there were too much for her to coordinate and she would have to leave her daughter behind. There was no extended family, her husband works 6 days a week in construction, and Rosa did not feel he would be able to care for Cristina independently.

This complex case addresses several areas requiring cultural consideration. Both mom and daughter have life-limiting conditions which require support and care. The complex factor of their limited access to care adds to the need for comprehensive assessment of the values, practices, beliefs, and goals of the family.

Questions to Consider in this Case

1. What cultural issues must be considered in this case, and how may these issues impact decision-making?
2. How may a palliative team be helpful to this family, and what resources may they access to assist with the cultural needs of this family?
3. What are some communication techniques that the nurse and other healthcare providers might use with this family?

Striving for Cultural Competence

All nurses should value the importance of being culturally sensitive and strive for cultural competence. This sensitivity and competence is especially vital for nurses working with patients with a life-limiting illness and their families.

Cultural competence refers to a dynamic, fluid, continuous process of awareness, knowledge, skill, interaction, and sensitivity.[12] While the term remains controversial, as some question whether true "cultural competence" can ever be achieved,[3] cultural competence remains an important outcome for nursing students[13] and essential for all nurses, as noted by nursing organizations worldwide.[14] Cultural competence is more comprehensive than *cultural sensitivity*, implying not only the ability to recognize and respect cultural differences but also to intervene appropriately and effectively.[15] According to Campinha-Bacote's model for enhancing cultural competence, there are five components essential in pursuing cultural competence: cultural awareness, cultural knowledge, cultural skill, cultural encounters, and cultural desire.[12]

Cultural Awareness

Integrating cultural considerations into palliative care requires, first and foremost, awareness of how one's own values, practices, and beliefs influence care. Cultural awareness begins with an examination of one's own heritage, family's practices, experiences, and religious or spiritual beliefs.[12] Cultural awareness challenges the nurse to look beyond his or her ethnocentric view of the world, asking the question, "How are my values, beliefs, and practices different from those of the patient and family?" rather than, "How is this patient and family different from me?" Exploring one's own beliefs by completing a personal self-assessment will raise an awareness of differences that have the potential to foster prejudice and discrimination and limit the effectiveness of care.[16] Often identifying more similarities than differences, the nurse and patient can recognize universal aspects of life, family, trust, love, hope, understanding, and caring, which will enhance the quality of care.

Cultural Knowledge

Acquiring knowledge about different cultural groups is the second component to striving for cultural competence, but knowledge alone is insufficient in providing culturally appropriate care.[12] Having in-depth knowledge of all cultural variations of health and illness beliefs, values, and norms is an impossible task. A suggested strategy is to identify the most common ethnic group/cultures living in the nurse's community and to integrate a basic understanding of norms and practices impacting issues likely to arise in palliative and end-of-life (EOL) situations.

It is important to be aware that knowledge gained of a particular group should serve only as a guide to understanding the unique cultural needs of the patient and family, which comes through individualized assessments. Relying solely on culturally specific knowledge to guide practice, rather than individual assessment, is incongruent with culturally competent care. Resources may also be helpful to assist the nurse in acquiring knowledge about specific groups including cultural guides, literature, and Web-based resources (examples listed in Box 37.2).[17]

Cultural Skill

Cultural skill is the third component of cultural competency.[12] Skills in cultural assessment, cross-cultural communication, cultural interpretation, and appropriate intervention can be learned. Multiple tools are available to assess cultural behavior and beliefs. For the new nurse, key assessment questions, applicable in the palliative care setting, may be helpful in guiding the assessment (Box 37.3). These questions, although useful to guide a discussion, should not replace patient and family interaction. Listening to the stories of heritage/family history and asking about their cherished practices and beliefs is an invaluable way to learn more about the patient and family and build a trusting relationship.

Cultural Encounters

The fourth component encompasses the concept of cultural encounters.[12] The more opportunities we have to engage with persons with differing values, practices, and beliefs, the more we learn about others and ourselves and the less likely we are to draw erroneous conclusions about each other. Active engagement with community leaders and use of learning tools such as case studies and role plays all help expose nurses to varied cultural experiences.[12] Increasing exposure to cultural encounters may also improve confidence in one's ability to meet the needs of diverse populations.[12]

Cultural Desire

The fifth and final component of Campinha-Bacote's model for cultural competence is cultural desire.[12] This is the interest and openness with which the nurse strives to understand patients and

Box 37.2 Web-Based Resources

Cross Cultural Health Care Program (CCHCP): www.xculture.org

- CCHCP addresses broad cultural issues that impact the health of individuals and families in ethnic minority communities. Its mission is to serve as a bridge between communities and healthcare institutions.

Diversity Rx: www.diversityrx.org

- This is a great networking website that models and practices policy, legal issues, and links to other resources.

EthnoMed: http://ethnomed.org/

- The EthnoMed site contains information about cultural beliefs, medical issues, and other related issues pertinent to the healthcare of recent immigrants to the United States.

Palliative Care Network of Wisconsin: Home of Fast Facts and Fast Fact CME
Fast Fact & Concept #78; Cultural Aspects of Pain Management: https://www.mypcnow.org/blank-a8lpj

- This website contains many "fast facts" regarding palliative care. Number 78 addresses important cultural considerations and provides assessment questions when working with patients in pain.

Fast Fact & Concept # 216: Asking About Cultural Beliefs in Palliative Care: https://www.mypcnow.org/blank-g562

- This resource offers a framework for assessing patient and family cultural needs by taking a "cultural history."

Office of Minority Health: https://minorityhealth.hhs.gov/

- This website has training tools for developing cultural competency.

Transcultural Nursing Society: http://www.tcns.org

- The society (founded in 1974) serves as a forum to promote, advance, and disseminate transcultural nursing knowledge worldwide.

families and the communities from which they come. Cultural desire is motivation to "want to" engage in the process of cultural competence as opposed to being "forced to" participate in the process. The desire is genuine and authentic. Such experiences lend opportunities for the nurse to grow both personally and professionally.[12]

Some researchers suggest that the term "cultural humility" is more acceptable than cultural sensitivity or cultural competence when trying to provide culturally appropriate care.[2,12] They have suggested that multiple generations of blended families and intercultural marriages have made it nearly impossible to know all about the healthcare practices of particular communities. These social scientists and writers recommend that nurses strive to mindfully respect each patient/family member as unique individuals rather than the components of culture (ethnicity, religion/spirituality, place of residence, etc.) that might label them.[18,19] We believe that integrating the proposed model of cultural competence with cultural humility into clinical practice will strengthen nurses' ability to respect and support patient and family wishes in palliative care settings.

Box 37.3 Key Cultural Assessment Questions

Formal cultural assessments are available for the nurse to use (see resources in Box 37.2). Remember that a checklist does not always instill trust. Listed here are some suggestions for ascertaining key cultural preferences from both patients and family caregivers.

Basic Assessment Questions

- Tell me a little bit about yourself (e.g., your family, your mother, father, siblings, etc.).
- Where were you born and raised? (If an immigrant, "How long have you lived in this country?")
- What language would you prefer to speak?
- Is it easier to write things down, or do you have difficulty with reading and writing?
- To whom do you go for support (family friends, community, or religious or community leaders)?
- Is there anyone we should contact to come to be with you?
- I want to be sure I'm giving you all the information you need. What do you want to know about your condition? To whom should I speak about your care?
- Whom do you want to know about your condition?
- How are decisions about healthcare made in your family? Should I speak directly with you, or is there someone else with whom I should be discussing decisions?
- Addressed to patient or designated decision-maker: Tell me about your understanding of what has been happening up to this point. What does the illness mean to you?
- We want to work with you to be sure you are getting the best care possible and that we are meeting all your needs. Is there anything we should know about any customs or practices that are important to include in your care?
- Many people have shared that it is very important to include spirituality or religion in their care. Is this something that is important for you? Our chaplain can help contact anyone that you would like to be involved with your care.
- We want to make sure we respect how you prefer to be addressed, including how we should act. Is there anything we should avoid? Is it appropriate for you to have male and female caregivers?
- Are there any foods you would like or that you should avoid?
- Do you have any concerns about how to pay for care, medications, or other services?

Death Rituals and Practices

- Is there anything we should know about care of the body, about rituals, practices, or ceremonies that should be performed?
- What is your belief about what happens after death?
- Is there a way for us to plan for anything you might need, both at the time of death and afterward?
- Is there anything we should know about whether a man or a woman should be caring for the body after death?
- Should your family be involved in the care of the body?

Cultural Assessment

Conducting a Cultural Assessment

There are many tools available to help with cultural assessment. These tools include the components of culture discussed throughout this chapter. Completing a cultural assessment involves asking questions that enhance the development of a trusting relationship. When meeting the patient and family early in the disease trajectory, the palliative care nurse has the advantage of time to establish such a relationship. Unfortunately, this luxury of time is not always available. The nurse must develop the skill of presence and active listening as these are often more beneficial than a standardized tool. Checklists do not necessarily build trust and can be burdensome. Asking the patient and/or the family member about him- or herself and then listening to those narratives is powerful. Simple inquiries into patient and family practices and beliefs can assist the nurse in understanding needs and goals of care, and these stories often give clues that may trigger further questioning. Box 37.3 provides examples of trigger questions.

Components of Culture

Race

The commonly held misconception that "race" refers to biological and genetic differences and "ethnicity" refers to cultural variation is outmoded. Race exists not as a natural category but as a social construct.[20] Any discussion of race must include the harsh reality of racism issues and disparities that have plagued society and continue to exist even today. Recent studies have demonstrated the discrimination of persons of certain races regarding healthcare practices, treatment options, and hospice utilization.[21] When viewed in relation to specific races, morbidity and mortality statistics point to serious gaps in access to quality care. Racial disparities are still evident worldwide, even after adjustments for socioeconomic status and other access-related factors are taken into account.[22]

There is often an underlying mistrust of the healthcare system. Memories of the Tuskegee syphilis study and segregated hospitals remain with older African Americans.[23] The combination of mistrust and numerous other complex variables influence palliative care issues such as medical decision-making and advance care planning.[24] Compounding the situation is the fact that healthcare providers often do not recognize existing biases within systems or themselves.[25]

Researchers have tried to identify causal mechanisms for healthcare disparities in psychosocial, cultural, and spiritual palliative care; however, the work is sparse and limited by methodological flaws. Evans and Ume[26] recommend using a conceptual framework such as that used in the National Healthcare Disparities Report[27] to explore causal mechanisms, which include access to care, receipt of care, quality of care, and examination of barriers, usage, and costs of care and effectiveness, safety, timeliness, and patient centeredness.

Ethnicity

Ethnicity refers to "a group of people that share a common and distinctive racial, national, religious, linguistic, or cultural heritage."[27] The values, practices, and beliefs shared by members of the same ethnic group may influence behavior or response. Ethnicity has been identified as a significant predictor of EOL preferences and decision-making.[28] Currently, there are more than 100 ethnic groups and more than 500 American Indian Nations in the United States.[27]

Ethnicity has been shown to influence utilization of hospice and palliative care service. Ethnic minority groups are less likely to use hospice services when compared with non-Hispanic whites. Furthermore, there has been little increase in hospice utilization in Black, Hispanic, or Asian populations in recent years.[28] Researchers have demonstrated an understanding of disparities in quality EOL care among ethnicities but have not yet identified why this is happening.[29,30] Further study into the multiple factors influencing utilization of these services is needed.[31]

Although an individual may belong to a particular ethnic group, he or she may not identify strongly with that group.[3,32] Members of the same family from the same ethnic group may have very different ideas about what is acceptable practice concerning important palliative care concepts such as communication with healthcare professionals, medical decision-making, and EOL rituals. In multigenerational families, some members may hold to the traditional beliefs and practices of their ethnic community of origin. Other family members may have a bicultural orientation, moving between the family culture of origin to the host society, and others may have left their cultural roots and identify with the host society. For example, in the United States, second- and third-generation members of immigrant families may be more assimilated into Western culture than first-generation members. This can lead to cultural conflicts within families around sensitive palliative care concepts.

The assumption that an individual will respond in a certain way because he or she is a member of an ethnic group contributes to stereotyping. The nurse should assess each individual's beliefs and practices rather than assuming that he or she holds the beliefs of a particular group. Note that many studies have demonstrated that regardless of race or ethnicity, all persons share common needs at the end of life: being comfortable, being cared for, sustaining or healing relationships, having hope, and honoring spiritual beliefs.[3,8,19,32,33]

Age and Developmental Stage

Age has its own identity and culture.[3] Age cohorts are characterized by consumer behaviors, leisure activities, religious activities, education, and labor force participation.[34] Each group has its own beliefs, attitudes, and practices, which are influenced by their developmental stage and by the society in which they live. The impact of a life-limiting illness on persons of differing age groups is often influenced by the loss of developmental tasks associated with that age group.[3]

Infant/Toddler

Although in modern society we expect that children will outlive their parents, every year more than 50,000 children die from various causes including congenital malformations, traumas, and acquired illnesses.[34] While many of the principles of adult palliative care can be applied to children, caring for an infant or toddler with a life-limiting condition or at end of life brings new challenges to a nurse, which can be difficult to manage without experience or preparation.

Palliative care principles can be applied at time of diagnosis, which for some parents is during pregnancy. Compassionate care should be offered to the family during this time and discussions should be facilitated to allow parents options regarding care and treatment.[34] The National Association of Neonatal Nurses has a position statement outlining the values and recommendations for palliative care with newborns and their families.[35] These recommendations include advocating for family-centered care throughout the illness trajectory and following the death of a child because family members will continue to require support as they cope with their loss.

School-Aged Children

Just as children develop and change as they grow, offering palliative care to children as they emerge from infancy and toddlerhood into the school-aged years, requires another set of skills for the palliative care nurse. Depending on the developmental level of the child at the center of the care, the focus should be to assist the child to cope with the illness and offer support to the family. Typically developing children during the school-aged years have fears as well as vivid hopes and dreams, all which must be acknowledged during difficult times of illness. School-aged children strive for increased independence and autonomy and seek opportunity for control and responsibility,[36] traits often diminished by necessary medical procedures, clinical appointments, tests, and hospitalizations. Friends and a sense of belonging to groups of peers is important for this age group, and children with life-limiting illnesses are often excluded or forced into more solitary activities. This can be isolating and painful for the school-aged child, and recognition of this can help build trust between a patient and nurse. Family members also need support to consider the wishes of the child and help facilitate what may be important to them during this time.

Adolescence

Cultural considerations with adolescents coping with serious illness bring yet another set of concerns for caregivers. An increased sensitivity to their appearance[36] can be agonizing for teens going through bodily changes beyond their control. Peer groups and acceptance remains important, although adolescents strive to secure their own identities, including their own ethical and moral decisions. Adolescents should be involved in all decision-making regarding their care. Future goals and plans are often considered, and the impact that a serious illness may have on this trajectory can be distressing to both the teen and family. Providers must be sensitive to the self-preoccupation that teens have and the often critical self-image or low self-esteem that may be a factor during these difficult times. Spiritual development can be helpful and is often explored during this time. This may be an important implication for practice when caring for an adolescent with a life-limiting illness.[37]

Young and Middle-Aged Adulthood

Serious illness is less common in young and middle-aged adults than in older adults. The death-denying society of the United States does not expect young or middle-aged adults to have to face life-threatening illnesses or death. For young adults (aged 21–40) and middle-aged adults (aged 41–60), developmental tasks include finishing their education, starting and engaging in a work and career, finding a life partner, establishing a long-term relationship, and starting a family. A serious illness can interfere with being able to accomplish any or all of these tasks. Research has shown that patients with dependent children have more worry and anxiety over the uncertainty of the future and time away from family for treatment than those who do not have children at home.[38]

Older Adulthood

The world's population is aging. By 2050, it is estimated that the number of individuals aged 65 and older will increase from 8.5% in 2015 to approximately 16.7% of the population.[39] The population in the United States mirrors that of the global rise in the older adult population, with those over the age of 65 predicted to more than double their numbers listed in the 2010 Census.[40] As the population of young-old (60–69), middle-old (70–79), and very old (80 and older) adults rises, the importance of addressing the unique palliative care needs of the older adult becomes more evident.[41] Each group of older adults has specific developmental tasks that reflect cultural traditions and range from positive experiences (e.g., retirement, grandparenting) to losses associated with aging (e.g., loss of independence, death of those close to them, and physical and mental health changes).

Cultural considerations related to this aging population include the impact of serious illness on finances, home environment, caregiving needs and availability, medical decision-making abilities, management of complex medication regimens and comorbid conditions, availability of medications, and pain and symptom management disparities. Cognitive changes make decision-making and patient safety critical issues across the aging trajectory.

As the adult population lives longer, spousal caregivers, who may also be among the very old, often have their own medical issues that may impact their ability to provide care.[42] Research suggests that informal caregiving can have a negative impact on the health of the family caregiver, highlighting the need for intensive monitoring of both patient and family caregiver.[43]

Gender

Gender Considerations

Cultural norms have guided specific roles for men and women regarding illness and EOL care. For some families, gender determines roles in decision-making and caregiving.

It is culturally sensitive to be aware of family dominance patterns in decision-making and determine which family member or members hold that dominant role. In some families, decision-making may be the responsibility of the female head of the family, in others the male head of the family or eldest son. For example, those of Asian ethnicity who follow strict Confucian teaching believe that men have absolute authority and are responsible for family decision-making.[17] When caring for families who adhere to these norms, discussing prognosis and treatment with a female family member is likely to cause the patient and family distress and may result in significant clashes with the healthcare team and mistrust. It is critical to ask every person and family who should have the responsibility for decision-making and never assume how that family functions.[19]

In addition to decision-making, cultural expectations exist regarding the responsibilities of caregiving. In many families, women have traditionally been expected to take on the role of caregiver when someone in the family is facing a serious illness. This responsibility, in addition to responsibilities at work and for children, has been overwhelming for many women, affecting their physical and emotional well-being. Research has demonstrated that female caregivers tend to experience greater caregiver burden, anxiety, and depression than male caregivers.[44] Supportive interventions for family caregivers, regardless of gender, are an essential component of palliative care.[19,45]

Gender Identity

One of the most profound gender disparities in the delivery of quality palliative care involves providing quality palliative care to those who are lesbian, gay, bisexual, transgender, or queer/questioning (LGBTQ).[42] It is recommended that the best way to address these disparities is by providing LGBTQ-inclusive palliative care rather than conceptualizing LGBTQ people as a "special population" that is separate from all others.[46] Acquaviva[46] suggests that making subtle changes in the way palliative care is delivered will allow for inclusive, nonjudgmental hospice and palliative care for all persons.

First, it is essential to use language that is nonjudgmental. It is not appropriate to assume an individual's gender identity based on biologic sex. Sex refers to biology and physiology. Gender identity refers to "that person's internal sense of being a man or a woman. Gender expression, or gender presentation is the way a person outwardly expresses that internal sense."[47] When meeting a patient for the first time, it is important to ask questions that are person-centered. Examples of those opening questions are listed in Box 37.4.

There are some particular aspects of palliative care where the LGBTQ population may be at risk. Ethical and legal issues related to advance care planning, healthcare decision-making, disposition of the body after death, and property ownership are particularly important to address early in care. Waiting until the end of life to have these discussions may be too late. Nurses play a major role in educating patients and families about the importance of appointing and documenting a healthcare power of attorney, especially for unmarried LGBTQ persons and those who may be estranged from family members.

Risk for discrimination of LGBTQ older adults has been brought to the forefront recently.[48] A report on the issues facing the aging LGBTQ population has highlighted concerns about discrimination from nursing home staff and mistreatment by roommates and other residents.[49] Antidiscrimination policies and staff education need to be put in place across the United States.

It is important to note that transgender individuals may have some unique health needs that can influence disease and symptom management in palliative care. Some transgender persons have had medical or surgical interventions to help them achieve their gender identity,[46] and these interventions may have implications on morbidity and mortality. For example, cross-sex hormone therapy may have a negative effect on cardiovascular disease and diabetes in transgender men but may have important psychological benefits, thus requiring a benefit–burden conversation in palliative and EOL care. However, many healthcare professionals are not knowledgeable about the risks associated with medical or surgical interventions that should be monitored closely. Nurses should be aware of the benefits and burdens these individuals face across the life span in order to support them in treatment decision-making.

Box 37.4 Questions Regarding Gender for Establishing Trust and Respect

- What name do you use?
- What sex were you assigned at birth?
- What gender do you identify as now?
- What gender pronouns do you use?
- Whom do you consider to be your "family"?

Language

It is essential to determine the dominant language and dialect spoken and the literacy level of both the patient and the family. If there is a language barrier, a professionally trained interpreter of the appropriate language should be contacted. This may include the use of a computerized interpreter service that offers secured services under the Health Insurance Portability and Accountability Act (HIPAA). If such services are not available, other health providers, ideally those trained in palliative care, may serve as interpreters. Family members should only act as interpreters in emergency situations and only if they agree to do so, as family members placed in this role may feel uncomfortable should sensitive issues or questions arise.[3,11] Always determine what is culturally appropriate to disclose prior to discussion regardless of who is involved in the communication of medical information.[2] When using an interpreter, direct all verbal communication to the patient/family rather than the interpreter. Ongoing clarification that information is understood is critical.

Religion and Spirituality

Religion is the belief and practice of a faith tradition, a means of expressing spirituality. Spirituality, a much broader concept, is the life force that transcends our physical being and gives meaning and purpose.[50,51,52] Although religion and spirituality are complementary concepts, these terms are often mistakenly used interchangeably. It should be noted that an individual may be very spiritual but not practice a formal religion. In addition, those who identify themselves as belonging to a religion may not necessarily adhere to all the practices of that religion. As with ethnicity, it is important to determine how strongly the individual aligns with his or her identified faith and the significance of its practice rituals.

Chaplains, clergy from a patient's or family member's religious group—ideally their own community clergy—are key members of the interdisciplinary palliative care team. Those who turn to their faith-based communities for support may find the emotional, spiritual, and other tangible support they need when dealing with a life-limiting illness.[53] Keep in mind, however, that some individuals who are struggling with misconceptions of the tenets of their own faith may experience spiritual distress and need spiritual intervention from caring chaplains or spiritual care counselors. Also, be aware that many community clergy are not trained in EOL care and may need assistance from the palliative care team in order to support the patient's spiritual journey.

Spirituality is in the essence of every human being. It is what gives each person a sense of being, meaning, purpose, and direction.[53] It transcends the self to connect with others and with a higher power, independent of organized religion.[3,27,33,50] One's sense of spirituality is often the force that helps transcend loss and suffering.[31,50,54] Spiritual distress can cause pain and suffering if not identified and addressed. Assessing spiritual well-being and attending to spiritual needs, which may be very diverse, is essential to quality of life (QOL) for patients and families facing serious illness and confronting end of life. For more information on spirituality, see Chapters 34 and 35.

Socioeconomic Status

One's socioeconomic status, which is usually measured as a combination of education, occupation, and income, is an important aspect of one's cultural identity, affecting physical and mental health and playing an important role in palliative care. Inequities in health distribution and resource availability are increasing in the United States and globally.[55] Individuals who are socioeconomically disadvantaged, with lower educational achievement, poverty, and poor health, face unique challenges when seeking healthcare and health insurance[55] and may struggle to navigate the healthcare system and to find information and support.

Financial costs, including those for medications, medical tests, and treatments not covered by limited insurance plans, transportation, and childcare add additional burdens. Regardless of financial status, an estimated 25% of families are financially devastated by a serious terminal illness.[3] Patients experiencing disease progression, or in whom treatment side effects preclude the ability to work, are forced to confront profound losses: loss of work and income, loss of identity, and loss of a network of colleagues.

While an exhaustive review of the impact of socioeconomic status on health and health outcomes is beyond the scope of this chapter, we discuss some important aspects that the palliative care nurse should consider in the following paragraphs.

Health Literacy, Health Numeracy, and Financial Literacy

Individuals who are socioeconomically disadvantaged may experience additional difficulties when attempting to understand medical terms and basic body functions, and when interpreting statistics and evaluating risks and benefits.[56] While no universal definition exists, most definitions identify *health literacy* as the degree to which an individual can obtain, process, and understand basic health information in order to make decisions related to health.[57,58] Even individuals with good literacy skills can have low health literacy, health numeracy, or financial literacy.[56,58]

Health numeracy is related to health literacy, referring to the degree to which individuals have the capacity to obtain, interpret, and process quantitative information for health behavior and decision.[59] Health numeracy includes four functional categories: basic numeracy skills (identify numbers and comprehend data), computational skills (ability to count, quantify, compute, and use simple manipulation of numbers or figures), analytical skills (e.g., inference, estimation, and proportions), and statistical numeracy skills (e.g., analytical skills plus the ability to critically analyze information and research findings and weigh risks and benefits).[59]

Financial literacy refers to an individual's ability to use knowledge and skills to manage financial resources effectively for life-long financial well-being.[60] Individuals who lack the ability to consider health insurance options, calculate out-of-pocket expenses, and navigate other complex financial choices may have more difficulty in making important health decisions.[58,61] Globally, financial illiteracy is widespread.

Individuals facing serious illness need information in a format and language that is easily understood in order to make informed healthcare decisions.[62] For individuals who are socioeconomically disadvantaged, the challenges just described regarding health, numeracy, and financial literacy may be more significant. Nurses can assist patients and family by considering whether the information they receive reflects their socioeconomic status, age, cultural background, language, and literacy skills.

Place of Residence

Access to services is challenging for some individuals depending on their geographic location. For those living in rural areas, access to palliative care services is inadequate when compared to urban areas.[63] While access to and availability of specialty palliative care services has seen an increase in the past few years,[64,65] internationally, research suggests that lower socioeconomic status is associated with lower use of palliative care services.[66] Factors that affect poorer utilization include an inconsistent number of service providers in disadvantaged areas and increased travel time to specialist palliative care providers and facilities.[66] Hospice services are also lacking in rural counties, with discrepancies between needed and received hospice care.[67] Recent developments, including community support, academic partnerships, and telehealth initiatives, suggest that improvement in access for the seriously ill and dying may be feasible in the most remote areas.[68]

Homeless Individuals

The homeless face significant mortality, comorbid conditions, and high disease burden compared to age- and sex-matched peers.[69] The last global survey of homelessness was completed by the United Nations in 2005 and estimated that 100 million people were homeless and that more than 1 billion people lacked adequate housing in both industrialized and developing nations.[70] In the United States, it is estimated that at least 500,000 persons are homeless, and that nearly 1.5 million people use homeless shelters.[71]

Many of the health, numeracy, and financial literacy concerns mentioned earlier may be present for homeless individuals. Additionally, individuals may not have a trusted surrogate decision-maker and may be estranged from family members.[72] Despite significant barriers to advance care planning with this population, research indicates that homeless individuals have the desire to complete advance directives when given the opportunity.[71–73]

Homeless persons with serious illness may have greater social challenges, mortality at a younger age, higher prevalence of physical symptoms associated with psychosocial distress, mistrust of the healthcare community, and a higher occurrence of psychological symptoms than the general population.[69,71,73] Individuals also experience a higher incidence of substance use, severe mental illness, and infectious diseases (e.g., HIV/AIDS, hepatitis C).[73]

Despite calls for improved palliative resources and access to services, the homeless continue to have limited access to quality palliative care services.[74] Access to transportation, stigmatization by healthcare providers, prioritizing basic needs of food and shelter, and ineligibility for health insurance may delay a person from accessing healthcare or obtaining adequate follow-up.[73,75] Healthcare professional attitudes (perceived or real negative stereotyping) and lack of experience may also contribute to existing barriers.[75]

Suggestions to improve palliative and hospice services for homeless persons include building trust and relationships, increasing collaboration between professionals, increasing flexibility within health services, and providing training and support for professionals working with homeless people.[75] Several examples of programs offer hope for homeless individuals facing serious illness, including shelter-based and street-based palliative care programs,[76] programs aimed at increasing advance care planning in the homeless population,[72] and increased education for health providers. With an increase in community-based palliative care, some of the access issues may begin to lessen; however, continuing financial concerns and adequate shelter and caregiving needs will require ongoing research and efforts in both rural and urban settings.

Prisons

Globally, the number of seriously ill and dying persons in prisons is growing. Most current literature focuses on US prison hospice programs or on identifying barriers to quality palliative and EOL care in prisons.[77] Examples of successful practices include the use of inmate volunteers alongside interdisciplinary teams and prison staff training and partnerships with local hospice organizations. Barriers to improved palliative care in prisons include mistrust between staff and prisoners, safety concerns, concerns regarding the use and potential misuse of opioids and other medications used to ameliorate symptoms, ethical dilemmas based on custody versus care, staff and public apathy toward rights to healthcare for this population, and debate over the use of compassionate release.[77]

Immigration Status

Immigrant populations face both cultural and logistical challenges when faced with serious illness and dying due to language differences, potential health literacy deficiencies, variations in family decision-making and role responsibilities, insurance barriers, and the possibility of lack of financial or social resources.[78] It is important to consider whether there are true disparities rather than differences in patient/family care preferences, as well as to consider professional bias toward perceived cultural differences when approaching goals of care discussions and assessments.[79] Over time, acculturation may decrease true variations in preferences; however, completing an in-depth cultural assessment is necessary to determine individual norms and preferences.

The number of undocumented immigrants varies worldwide. It is estimated that there are approximately 11 million unauthorized immigrants in the United States in 2015,[80] many of whom are educationally and socioeconomically disadvantaged and living in rural areas without access to healthcare.[81] For undocumented immigrants, challenges to optimal healthcare include limited social support, geographic distance from family, language and cultural barriers, financial concerns, and fear of deportation. Most are not insured, and access relies on provisions for emergency medical treatment through the Emergency Medical Treatment and Labor Act (EMTALA) and safety net clinics.[81–83] Disparities in hospice access for unauthorized immigrants exist in areas where most hospice care is delivered by small, for-profit agencies.[84] Health insurance and healthcare access is limited. Undocumented individuals are excluded from federally funded insurance options (full Medicare and Medicaid). This lack of both insurance and access to needed health services negatively impacts patient and family care and support.

Disability Status

Individuals with physical disabilities or mental illness are at risk of receiving poorer quality healthcare. Those with differing abilities constitute a cultural group in themselves and often feel stigmatized. This discrimination is evident in cultures where the healthy are more valued than the physically, emotionally, or intellectually challenged.[3] If patients are unable to communicate their needs, then pain and symptom management and end-of-life wishes are often not addressed. Additionally, this vulnerable population's losses may not be recognized or acknowledged, putting individuals at risk for complicated grief. Taking time to determine an individual's goals of care—regardless of differing abilities—and identifying resources and support to improve QOL is essential.

Essential Cultural Concepts in Palliative Care

Culture impacts all aspects of palliative care. This section focuses on key palliative care issues and concepts that are heavily influenced by patient and family values, practices, and beliefs. Communication, medical decision-making, pain and symptom assessment and management, nutrition, and EOL rituals are presented.

Case Study: The Impact of Culture on Palliative Care

Mr. J was a 72- year-old African American man, diagnosed 3 months ago with stage IV non–small cell lung cancer, with metastases to the spine and brain. The palliative care team of a large academic medical center was called to offer a consult during a recent hospitalization for uncontrolled hip pain and dyspnea. He had received palliative radiation for his back pain and brain irradiation to his three metastatic lesions previously.

Since his diagnosis, he has been living with his daughter and her family (three children, ages 10, 14, and 17) in a small apartment in the inner city because he is unable to care for himself. He refused to take opioids for his hip pain and dyspnea, stating, "I don't want to become an addict like my brother." Mr. J's daughter did not want to have him living at her house taking opioids because her oldest daughter has been treated for addictive disease and, "I can't have those drugs in my house."

The oncology and palliative care team agreed that the patient had progression of his cancer, as evidenced by new bone metastases in his hips and new liver metastases. With his past medical history of type 2 diabetes, hypertension, and renal insufficiency, no further cancer treatment was recommended. The oncologist met with the patient and his daughter and recommended hospice care. Mr. J was furious that "they are giving up on me," and his daughter states that "they are only suggesting this because they don't want to take care of Medicaid patients like my father at this hospital."

Questions to Consider in this Case

1. What cultural considerations may have contributed to the challenges of pain and symptom management for Mr. J?
2. What cultural issues may have influenced Mr. J and his daughter in their mistrust of the healthcare system and his oncology care?
3. What communication strategies may have helped with the complexity of the patient's and daughter's fears and concerns?

Communication

Communication is the foundation for all encounters between nurses, patients, and family members.[85] When the nurse and the patient–family unit are from different cultural backgrounds, discussing news regarding serious illness or a poor prognosis can be challenging if the nurse is not aware of potential cultural conflicts. Communication disparities may lead to poorer outcomes and reduced patient and family satisfaction.[16,86] The establishment of a trusting relationship with the nurse, where the nurse seeks to understand the unique concerns of the patient and family, provides a foundation for all future communication and decision-making.[19]

Communication is an interactive, multidimensional process, often dictated by cultural norms, and it provides the mechanism for human interaction and connection. Given the complexities of communicating diagnosis, prognosis, and progression of a life-limiting disease, there is no "one size fits all" approach.[87] Cultural assessments, including cultural norms related to communication, should occur early in the initial assessment, and findings should be clearly documented and shared with all health providers involved in the care of the patient and family (Box 37.5).

Box 37.5 Culturally Competent Communication Skills and Best Practices for Palliative Care

1. *Foster respect.* Baseline assessment and documentation should include primary language/dialect. Determine need for professional interpreter services. Determine how individuals prefer to be addressed and who should be involved in giving/receiving medical information and participating in decision-making, especially in regards to treatment options for serious illness.
2. *Engage in person-centered conversations through active and reflective listening.* Reflective listening involves hearing, understanding, retaining, analyzing, and evaluating information. Get to know the patient as an individual with values, beliefs, and hopes for the future. During conversations, be aware of cultural implications of nonverbal communication. Is eye contact or touch acceptable during active listening or is it disrespectful?
3. *Provide presence.* This is the greatest gift nurses can give their patients and families. Listen to the stories, life goals achieved, and future goals. Pull up a chair for a few minutes and let the patient tell you what is important to him or her. Show empathy and compassion; be quiet/reflective during times of silence.
4. *Assess the patient's interpretation of what is important in life, what gives life meaning for them.* Understanding what is important to the individual and those closest to him or her will assist in individualizing the palliative care plan. Support the patient's strengths and encourage the patient to maintain hope. Life review can help identify what gives life meaning.
5. *Assess and address religious and spiritual preferences and concerns.* It is important to understand the role that a religious/faith community and spiritual beliefs and practice play in the patient's life. Consider including clergy and others that the individual/family identifies as key supports. Offer spiritual care (books, music, rituals, meditation, etc.) to enhance healing and peace.
6. *Demonstrate consideration of patient's privacy, decision-making strategies, and experience of loss and grief.* Early assessment of cultural issues related to beliefs about disclosure of diagnosis and decision-making preferences will ensure that care is given in ways that respect patient and family values. Observe for signs and symptoms of anticipatory or complicated grief and refer to appropriate interdisciplinary team members.
7. *Assess patient and family knowledge of disease trajectories, if culturally appropriate to discuss.* Assess and address distressing symptoms, side effects of treatment, and likely disease progression. Reaffirm goals of care and attempt the relief of symptoms and other concerns. Incorporate preferred healing practices and traditions. Discuss early access to hospice care to support goals as disease progresses.
8. *Anticipate times when communication will be difficult.* Dealing with serious illness is often stressful. Be proactive by anticipating situations when communication may be difficult (i.e., breaking bad news, holding family meetings, and helping patients and family members communicate last wishes at end of life). Utilize appropriate interdisciplinary team members to provide support to the patient and family during these difficult times.

Source: Adapted from Reference 34.

Providing presence and active listening are the most important communication techniques for the nurse to master. Elicit patient and family concerns, customs, norms, beliefs, and values, and take time to reflect back what is heard. Encourage patients and families to also reflect back what they have heard. Listening to words alone is not enough. Pay attention to nonverbal cues (e.g., gestures, posture, use or avoidance of eye contact). Nonverbal communication will give valuable information and insight into the emotional impact of what is being said and will help inform the clinician regarding how to behave as well. The reader is referred to the Communication in Palliative Care, Chapter 5 for further discussion on this subject.

Medical Decision-Making

Over the past 45 years in the United States, ethical and legal considerations of decision-making have focused on patient autonomy.[28,53] This focus replaced the more paternalistic approach—decision-making as solely the physician's responsibility—with an approach that emphasizes a model of shared responsibility with the patient's active involvement.[24] The Patient Self-Determination Act of 1991 sought to further clarify and to protect an individual's healthcare preferences with advance directives.[88] The principle of respect for patient autonomy points to a patient's right to participate in decisions about the care he or she receives. Associated with this is the right to be informed of diagnosis, prognosis, and the risks and benefits of treatment to make informed decisions. Inherent in the movement for patient autonomy is the underlying assumption that all patients want control over their healthcare decisions. Yet, in fact, for some individuals, patient autonomy may violate the very principles of dignity and integrity it proposes to uphold and may result in significant distress.[53]

This European-American model of patient autonomy has its origin in the current dominant culture, a predominantly white, middle-class perspective that does not consider diverse cultural perspectives.[3] In fact, in some cultures, patient autonomy may not be viewed as empowering but rather as isolating and burdensome for patients who are too sick to have to make difficult decisions.[53]

Emphasis on autonomy as the guiding principle assumes that the individual, rather than the family or other social group, is the appropriate decision-maker.[24] However, in many non–European-American cultures, the concept of interdependence among family and community members is valued more than individual autonomy.[28,53] Cultures that practice family-centered decision-making, such as the Korean American and Mexican American cultures, may prefer that the family, or perhaps a particular family member rather than the patient, receive and process information.[27,53] The traditional Chinese concept of "filial piety" requires that children, especially the eldest son, are obligated to respect, care for, and protect their parents.[17] Based on the values and beliefs of this culture, the son is obligated to protect the parent from the worry of a terminal prognosis.

Although full disclosure may not be appropriate, it is never appropriate to lie to the patient. If the patient does not wish to receive information and/or telling the patient violates the patient's and family's cultural norms, the healthcare provider may not be respecting the patient's right to autonomously decide not to receive the information. Some cultures believe that telling the patient he has a terminal illness strips away any and all hope, causes needless suffering, and may indeed hasten death.[34,53] For example, for those adhering to traditional Navajo values, imposing negative information, such as prognosis of a life-limiting illness, on the person who is ill is a dangerous violation of their values.[53]

The nurse must consider the harm that may occur when the health system or providers violate cultural beliefs and practices. Assessing and clarifying the patient's and family's perspectives, values, and practices may prevent a cultural conflict.[3,16] The nurse is in a key position to address these critical patient and family issues (see Box 37.3 for examples of questions to ask). By asking how decisions are made and whether the patient wishes to be involved in both being told information or participating in the decision-making process, nurses respect patient autonomy and honor individual beliefs and values.[16]

Pain and Symptom Assessment and Management

It is important to remember that the acknowledgment and expression of pain and symptoms is heavily influenced by culture. Assessment must be performed with a cultural lens. For some, even the word "pain" has a negative connotation and some patients may not answer the assessment questions when those terms are used. For example, in certain cultures, it is unacceptable for a male to report pain; admission of pain is a sign of weakness.[3] These individuals may respond more openly to questions about "discomforts," "something hurting you" or "aching," rather than pain.

The same is true when assessing for symptoms. For example, depression, a common symptom in palliative care, may not be able to be assessed simply using the standard assessment question, "Are you depressed?" Patients who are unable to admit depression due to stigma or other cultural considerations may be open to discussing feelings of "sadness" or "having no energy" or "no interest in things that usually bring joy." An association between the report of symptoms and symptom distress has been reported. Individuals from Asian-speaking communities in the United States have reported low symptom distress because of their fatalistic beliefs regarding acknowledging symptoms and their meaning. Sensitivity to the language used in assessment of pain and symptoms is essential for an accurate assessment.

Managing pain and symptoms may also be culturally challenging. If a patient and family has relied on remedies commonly used in their culture to manage symptoms, insisting on more Western-style medications/interventions is inappropriate and can result in a cultural clash and an ethical dilemma. It is important that the nurse work together with the patient and family and the team to identify safe, effective, and culturally respectful ways to address pain and symptoms associated with the serious illness.

Research has demonstrated that racial and ethnic differences continue to exist in pain assessment and pain management.[21] The unmet needs for good pain management in an African American population when compared to a Caucasian population at the time of a palliative care consult highlights this issue in the United States.[89] Western providers are reported to underestimate pain in 75% of African Americans and 64% of Hispanics experiencing pain.[90] It is important to be aware of these disparities in delivery of quality palliative care and work to ensure equal care for all.

Nutrition

One of the most central aspects of caring for each other in nearly every culture is feeding. Food and nutrition are essential human needs, and sharing food together is an essential social interaction for families and communities. When patients with serious illness no longer have the desire or ability to take food in, families often become distressed. Many mistakenly believe that providing food or fluids at the end of life will prolong survival.[91] Research has shown that the burdens associated with medically administered nutrition or hydration at end of life usually outweigh the benefits.[58] Families need to be educated about the burdens and taught ways to provide care other than making food or feeding. For example, teaching them how to do good oral care for the patient, keeping the mucous membranes and lips moist, will allow them to provide comfort and physical caregiving. Encouraging them to offer small bites of favorite foods for pleasure and tasting can be enjoyable for the patient and family. This is especially important when certain cultural foods are essential for QOL.[8,33,91]

End-of-Life Rituals

It is critical that the nurse explores what cultural rituals should be honored as death approaches, at the time of death, and immediately after death. These important rituals and practices should be known well in advance of the death, if possible. Rituals are important social aspects of care that can provide a means to express emotions, ease anxiety, and offer structure in times of distress.[92] However, if the patient and family are not given the opportunity to engage in valued rituals, needless suffering occurs and the grieving process may be complicated. Memories of the loved one's death will stay with the family forever.

Examples of rituals prior to death that may be offered include, among others, having a priest administer the Sacrament of the Sick to practicing Catholics. Those who are practicing Hindi may prefer to die at home, lying on the floor close to Mother Earth.[52] Every effort should be made to get the patient home and honor that valued practice. Immediately after death, for those adhering to the Muslim faith, the body should be placed facing Mecca or the East. This should be known ahead of time and honored immediately following death. In the Orthodox Jewish tradition, as well in other cultures, care of the body after death is gender-dependent.[17] Therefore, it is important after death that a female nurse not clean a male body if the family is adhering to Orthodox practices.

Rituals that are spiritual and nondenominational can be a tremendous support to families after the death of their loved one. A bathing and honoring ritual, developed by hospice nurses at Cottage Hospice in California, has been shown to be a meaningful way to respect the patient's body, honoring the person-centeredness of that individual and comforting the family.[93] This ritual can be offered by nurses in acute care, hospice or home care, and long-term care.

Finally, rituals that honor the work that professionals have done in caring for the deceased patient and family are extremely important to our profession. Taking a moment at the time of death to honor the person who has died as "somebody's mother, somebody's daughter, somebody's loved one" is essential to healthy grieving for the healthcare team. A ritual called "The Pause," performed after death in the emergency room or in the intensive care unit, is appropriate in all healthcare settings and important in preventing compassion fatigue in healthcare workers.[94]

Conclusion

Given the changing population of the United States, we as nurses must advocate for the integration of cultural considerations in providing comprehensive palliative care. It is imperative that each of us move beyond our own ethnocentric view of the world to appreciate and respect the similarities and differences in each other. We are challenged to embrace a better understanding of various perspectives. Striving for cultural competence first requires an awareness of how one's own cultural background impacts care. In addition, acquiring knowledge about cultures and developing skill in cultural assessment and communication are essential to improving palliative care for patients with life-limiting illnesses and their families. Most importantly, maintaining a sense of cultural humility, caring for each patient/family member as a unique human being with unique needs, and attending to those needs with dignity and respectfulness are the essence of providing culturally sensitive care.

This chapter encourages nurses to integrate cultural assessment and culturally appropriate interventions into palliative care. It is the hope of the authors that readers will enrich their practice by seeking new knowledge about different cultures through available resources and, most importantly, by respectfully interacting with the most valuable resources on cultural considerations we have—our patients and their families.

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CHAPTER 38

Older Adult Patients in the Community

Carol O. Long

Key Points

- Caring for older adults with serious and life-limiting illness who reside in the community requires special considerations. Known as geriatric palliative nursing, a comprehensive, holistic, and person-centered approach incorporates physical, psychological, social, and spiritual care to enhance quality of life for older adults.
- Community-based palliative care for older adults refers to care of the person living within the environment in which they reside.
- Geriatric palliative nursing care encompasses targeted assessment and management strategies specific to older adults.
- Community-based palliative care of older adults includes general principles related to ethics and advocacy.

Introduction

Palliative care nursing for older adults continues to evolve, with expanded inquiry into all of the elements that support dignity, relief of suffering, and quality of life (QOL) along the trajectory of illness toward the end of life. Older adults will encounter increasing physical limitations and comorbidities and the potential for diminished cognitive ability. These progressive losses, that span ages 65 to 100, can be challenging for the patient and family. Nursing care of older adults in the community requires a unique set of assessment and management skills for the palliative care nurse. The purpose of this chapter is to provide an overview of the complexities of aging and the mechanisms necessary to allow individuals to age successfully until the end of life. The key tenets of palliative care nursing for patients residing in the community are described.

Aging in America

Older adults make up one of the fastest growing demographic groups in the United States. According to the US Census Bureau, there are approximately 47.8 million adults aged 65 years and older in the United States, an increase of more than 8 million since 2000.[1] To date, one in seven Americans (15% of the population) is an older adult.[2] Of those over the age of 65, the greatest projected increase is in the 85 and older segment, estimated to grow from 6.3 million to 14.6 million by 2040.[2] This age group is most likely to require long-term care or community-based nursing services due to increasing difficulty with activities of daily living (ADLs), many chronic conditions, and dementia. This group is expected to be 29.7% of the population in 2050.[3] Similarly, 21.8% of noninstitutionalized persons age 65 and older report that they are in fair or poor health.[4]

The United States is also becoming more diverse. In 2015, a record high number of 22% of older adults reported membership in one or more racial or ethnic populations. By 2050, minority populations are projected to increase from 14% to 22.7% of the older adult US population.[3] Educational attainment has improved over the past 20 years, with 85% of older adults completing high school.[2] Sources of financial income vary widely with most (84%) receiving Social Security payments in addition to income from other assets and pensions.[2] However, one in seven older adults (15%) experiences poverty.[5]

The average life expectancy in the United States in 2012 was more than 78 years compared to 50 years of age in the early 1900s.[6] Life expectancy continues to increase as people aged 65 and older can anticipate adding 19.4 years to their lifespan (20.6 years for females and 18 years for males). Women aged 65 and older (26.7 million) continue to outnumber older men (21.1 million), while older men (70%) are more likely to be married than older women (45%).[2]

As the average life expectancy has changed, so have the causes of death. The 10 leading causes of death in 2014 account for approximately 75% of all deaths for those 65 years and older (Box 38.1).[6,7]

Only 1.3 million adults live in residential care settings; thus, the majority of older adults live in the community, of which 13.6 million live alone.[2,8] *Community-based care* refers to care delivered in the environment in which a person lives, largely excluding residential skilled nursing care and acute care settings. Among older adults, 61% prefer to age in their own homes.[9] However, where older patients live may not be where they die. While there has been a shift toward more home-based palliative and hospice care for older adults, many still live out their remaining days and die in the hospital, emergency department, or intensive care unit.[10] To date, 84% of hospice patients are aged 65 and older.[11] Correspondingly, two out of every five Americans aged 65 and older have not completed any advance directive. Thus, the care that people would choose at the end of life may not be the care that they receive, and chronically ill older adults may receive expensive futile care.[12]

In summary, the 65 and older demographic sector is forecasted to increase as more than 10,000 people turn 65 each day.[13] The shift to an aging population and the inherent complexities in community-based healthcare are expected to continue until 2060. As such, palliative care nursing will increasingly shift its attention to the care provided to older adults and particularly those living in the community.

Box 38.1 Ten Leading Causes of Death

Diseases of the heart	25.5%
Malignant neoplasms	21.5%
Chronic lower respiratory diseases	6.5%
Cerebrovascular disease	5.9%
Alzheimer's disease	4.8%
Diabetes mellitus	2.8%
Accidents	2.5%
Influenza and pneumonia	2.3%
Nephritis, nephritic syndromes, and nephrosis	2.1%
Septicemia	1.5%
Other	24.5%

Case Study: A Community-Living Older Patient

"Isabel Menendez, age 68, was diagnosed with heart failure last year. On any given day, Mrs. Menendez, a proud Hispanic women and mother of six grown children, would have told you that her life had been blessed. Married for more than 40 years, she and her husband had lived in an Arizona rural community their entire lives. To her, home and family was everything. So was her local Catholic church, her neighbors, and afternoons watching *telenovelas*. Three years ago, her life changed after suffering an acute myocardial infarction while at the grocery store. After experiencing extensive cardiac damage, Mrs. Menendez became oxygen-dependent and took many medications that often made her drowsy. Adamant to stay at home, her family had pondered what could be done to promote her independence at a time of physical compromise. She was often sad and lamented that "my best days are behind me and I have nothing to look forward to." At her last cardiologist appointment, Mrs. Menendez reported increasing dyspnea, and she was admitted to the hospital. Her ejection fraction was 38%, and her prognosis was poor. She had yet to complete her advance directives. Two more times, she entered the hospital and was discharged to her home, a bit weaker and more dependent than ever before. While not yet terminal, the hospital team believed that a palliative care consult was necessary. With a desire to go home, a community-based palliative care team met with Mrs. Menendez and her husband to discuss how to best meet her goals of care while providing the symptom relief necessary to make her comfortable. Future discussions would include hospice care but, for now, the team contemplated what physical, psychological, social, and spiritual components needed to be addressed to support the QOL that Mrs. Menendez desired.

This case study illustrates episodic setbacks that punctuate the downhill trajectory experienced by Mrs. Menendez and others in their aging years. Most often, older adults want to remain at home during their final days. Expert nursing knowledge and skills are necessary to maintain a safe and caring community-based approach for older patients.

The Aging Adult

Aging is an evolving, complex biological process that begins at birth. The course of aging is influenced by a person's past experiences, the environment, family and home life, physical and mental health factors, culture, and the community in which a person resides. Being mindful of mind, body, and spirit interrelatedness, from wellness through illness and along the continuum of care, is the essence of nursing in the care of older adults. Geriatric palliative nursing care incorporates physical, psychological, social, and spiritual care for those who are seriously ill until the end of life. Highlighting the key aspects of aging illuminates the opportunities available for community-based palliative care nursing (Box 38.2).

Box 38.2 Indications for Geriatric Palliative Care

- Individuals with progressive complex healthcare needs
- Significant symptom distress
- Functional deficits
- Number and complexity of chronic, comorbid chronic conditions
- Prevalence of debilitating geriatric syndromes

Physical Well-Being

Age-Associated Changes and Chronic Conditions

Aging, independent of disease, is variable from one person to the next. Numerous age-associated physiological and anatomic changes occur across all organs and systems as a normal consequence of aging but are more pronounced for individuals age 85 and older.[14] Decreased or diminished cardiac reserve, vital capacity and forced expiratory volume, oxygen consumption, cerebral blood flow, muscle mass, bladder wall elasticity, and renal function, to name a few, are possible age-associated changes seen in older adults. Age-associated sensory changes include presbycusis, vision changes (e.g., decreased visual acuity, problems with night vision), and changes in taste and smell which may contribute to compromised safety or other living adjustments. In one study, olfactory impairment was associated with an increased risk of mortality in older adults.[15] Other changes may ultimately lead or predispose individuals to disease, advanced medical conditions, or geriatric syndromes.[14,16] As such, physiologic and functional age-associated changes must be differentiated from pathological conditions or diseases to guide interdisciplinary team (IDT) recommendations that address the patient and family goals of care.

Chronic Conditions

Older adults are likely to encounter multiple chronic conditions as they age, and the primary cause of death in adults aged 65 and older is chronic disease.[17] It is estimated that more than 50% of older adults have one or more chronic diseases.[18] The increasing effects of disability related to chronic illness may compromise independence and QOL. As expected, functional disability associated with chronic conditions increases with age. The overall cumulative effect may significantly impact the older adult's well-being, especially when facing a serious or terminal condition.

Increasing comorbid or multimorbid conditions in older patients are likely to lead to increasing risk of death.[19–21] Multimorbidity may lead to further physical and functional decline and contribute to increasing complexity of care for palliative care clinicians in community-based settings.

Geriatric Syndromes

The term *geriatric syndrome* is used to describe an array of clinical manifestations that do not fit a discrete disease or medical condition category.[22] Geriatric syndromes are common in older adults and are most often linked to functional decline, decompensation, and poor health outcomes. Dementia, depression, frailty without a known cause, urinary incontinence, pressure ulcers, thermodisregulation, self-abuse or neglect, failure to thrive, syncope, falls, sleep disorders, atypical presentations, and delirium are geriatric syndromes, to name a few.

There is no uniform consensus about the total number of geriatric syndromes nor is it known how many older adults are afflicted with these conditions. Over the life course, many older adults may experience multiple syndromes or ones that cascade and lead to additional syndromes. Patients who are more ill or frail, with dementia or delirium, impaired homeostasis, or low body mass index are more likely to face increased mortality compared to the average in other older adults; the ratio of risk of geriatric syndromes to mortality increases as one ages.[20,22] Accordingly, geriatric syndromes and their associated risks may lead to symptom distress that requires palliative care interventions and may be more difficult to detect within community-based or primary care settings (Box 38.3).

Box 38.3 A Geriatric Syndrome: Falls

The propensity for unintentional falls is considered a geriatric syndrome. Falls are a leading cause of injury in the community (e.g., fractures and traumatic brain injury) and fatal deaths in older adults.[23] While falls, in and of themselves, do not require palliative care or hospice, falls in conjunction with other geriatric syndromes, as in dementia (e.g., Alzheimer's disease) or delirium, and coupled with comorbid or multimorbid conditions may be indicative of a downward decline in older adults. Thus, palliative care should be considered. See *ConsultGeriRN.org* for a complete review of common geriatric syndromes and conditions in older adults; access the *TryThis* series with numerous tools and instruments to use in the care of older adults. https://consultgeri.org.

Functional Status

Over time, older adults are at risk for increasing disability and functional decline due to sudden or chronic medical or mental health conditions. In 2015, 35% of older adults living in the community indicated that there was some type of disability, such as difficulty related to ambulation (23%), hearing deficits (15%), cognitive impairment (9%), compromised self-care (8%), and vision difficulties (7%). However, the same percentage indicated that their health was excellent or very good, while 22% reported fair to poor health status.[1,2,4]

Additionally, 30% of older adults age 65 and older living at home report difficulty in performing one or more activities of daily living (ADLs) in addition to one or more instrumental activities of daily living (IADLs). Arthritis, cancer, hypertension, and diabetes are commonly reported diagnoses for people age 75 and older. In general, noninstitutionalized older people report significant difficulty in doing errands alone and report diminished cognitive ability necessary to concentrate, remember, or make decisions. This escalates as people age and is more common among women compared to men.[4] Thus, the assessment of IADLs and basic ADLs is necessary in community-based palliative nursing care.

Finally, aggressive pain and symptom management is a core component in palliative care nursing and is addressed elsewhere in this textbook. General assumptions that pain and other physical deficits are a normal consequence of aging need to be dispelled and evaluated for treatment and aggressive comfort management.

Psychological Well-Being

Mental Health and Cognition

The mental health of older adults is largely underassessed and underaddressed. This is often due to the public stigma of mental illness or lack of understanding by clinicians regarding the necessity of evaluating depressive disorders, which is the most prevalent mental health condition in people aged 65 and older. Older adults living in the community may go day to day with mental health needs unnoticed. Evidence shows that the presence of depressive disorders can adversely affect the course of treatment and patient outcomes for older adults who have chronic diseases.[24] Older adults with multiple chronic and mental health conditions, such as depression and anxiety, and with greater illness burden are at risk for compromised lower self-confidence.[25] There is no evidence that older adults experience age-associated cognitive changes as they age.[26] However, individuals with dementia require palliative care because these conditions are considered terminal. Evaluating the mental health and cognitive abilities of older adults is an important consideration in geriatric palliative nursing care within the community.

Loss and Grief

Older adults encounter numerous losses as they age. The progressive or sudden loss of physical independence due to a medical condition or cognitive ability or sensory functions (hearing and vision) may be a constant reminder of one's own morbidity and mortality. For some, the death of close friends and family members may lead to depression, isolation, and despair. Shrinking social networks due to deaths and other physical or social losses (e.g., reduced mobility, driving cessation, lack of transportation) may compromise QOL. The progression from independence to dependence on others or living alone and later living in a nursing care facility are major losses for older adults. Suffering emerges as the individual tries to find stability and the opportunity for growth amid loss and resulting grief. Balancing the opportunity to live life fully with multiple losses and grief becomes life's biggest challenge for older adults.[27] Vigorous assessment and attention to single and cumulative loss and grief is essential in community-based care for older adult patients.

Person-Centered Care and Communication

Person-centered care is an essential element in community-based care for older adults and the cornerstone of palliative care nursing. While not widely studied in palliative care yet, recent research about older adults with chronic conditions indicates that the person-centered approach (care that is holistic, empowering, respectful, individualized, and dignified while promoting self-determination and purposeful living) improves satisfaction and quality of care in older adults with chronic conditions.[28–30] What remains is the need to formalize a definition and operationalize the key attributes of person-centered care within a community-based setting for older adults.

As such, acquiring excellent communication skills is a core competency and necessary component of person-centered care. Epstein and Street's seminal work in patient-centered communication in cancer patients identified six core functions necessary to provide better health outcomes: (1) fostering healing relationships, (2) exchanging information, (3) making decisions, (4) responding to emotions, (5) enabling patient self-management, and (6) managing uncertainty.[31,32] Patient-centered communication leads to enhanced QOL, treatment adherence, and self-efficacy. The inclusion of family members is vital in all communication efforts.[33] Palliative care nurses can intervene with older adults and families to diminish suffering by being present during conversations with patients and families while advocating for, being supportive of, and preserving dignity.

Spiritual Well-Being

Spirituality is integral to the care of the whole person. Finding meaning in life and redefining beliefs and values may be pivotal concerns for adults as they age and encounter life-changing medical events. Most of the research on spirituality and aging has been related to religion and health outcomes, thus the entire spectrum of spirituality and aging remains largely untapped.[34] Learning more about a person's faith or religious affiliation and spirituality is a core component of palliative care nursing. Integrating spirituality into the plan of care is a necessity. Organizational programs within communities may augment services provided by the palliative care team.

Social Well-Being

Evolving Living Arrangements

Our communities today are faced with pressing social issues related to the safety and sustainability of older adults living at home. Older people live in a variety of community settings across rural and urban America, spanning from independent living to institutionally based care. Most older adults prefer to "age in place," meaning that they prefer to live at home until their death. However, as older people age, they are more likely to live in care facilities, such as nursing homes, or move in with family members. Others may live in assisted living facilities, congregate housing or shared homes, and a myriad of other housing options which may be considered part of the community-based network. The primary causes for institutional placement are related to increasing physical or cognitive changes that result in dependency upon trained care providers to meet self-care deficits. Even so, more than 12 million households are managed by adults aged 75 or older, many of whom face the day-to-day effort of ongoing maintenance and general upkeep while living on a limited or fixed income.[1] It is estimated that 29% of noninstitutionalized adults live alone, and almost half of older women (46%) live alone by age 75.[1] Over time though, obstacles to continuing independence and autonomy may pose challenges for older adults and even more so if their health declines.

The potential for an unsafe home environment is also very real, especially with multilevel homes or apartments and other factors that may pose challenges for older adults, such as poor lighting or kitchen or bathroom hazards. Others have transportation problems, thereby limiting access to community and health resources in a timely manner. Older adults may access other community-based resources, such as adult day care and either skilled or personal home health care. Palliative care may be provided at an outpatient or independent home setting, bridging across many healthcare settings. Hospice care is available during the terminal stages of the person's life, and this care is available at home, within an inpatient setting, or nursing care facility.

Finally, transitions in care and in living arrangements are likely to occur as the older adult encounters changing health conditions that may tax the capacity of the family, financially or otherwise, to provide needed care and support. Other factors facing communities today are those who are homeless, disenfranchised from their family members for a myriad of reasons, and the unfriended. With many older adults living alone, it is necessary to assure that personal connections to the larger social and spiritual/religious communities are evaluated and included in the plan of care. Linking palliative care services and resources along the continuum of care is a significant concern for older adults living in the community.[35] If an older adult patient has been hospitalized, impeccable discharge-planning from acute care with insight into the home and family situation is necessary.[33,35]

Family and Caregivers

Formal and informal caregiving is common in community-based care. Formal caregiving is generally personal care services provided by paid direct care workers and other home help support staff from local agencies. Payment for this care generally comes from out-of-pocket, long-term care insurance, or home- and community-based services for those who are eligible. In general, informal caregivers are family members who provide unpaid care in response to an illness or functional impairment in a chronically ill older adult, partner, friend, or neighbor that exceeds the level of care and support typical in family relationships.[36]

Informal family caregivers may encounter caregiver burden and stress, physical distress, and increased financial burden related to the breadth and depth of caregiving. Many individuals would be institutionalized if caregiving at home was not available. It is estimated that more than 17.7 million family members provide unpaid care for older adults in the home.[37,38] Most of the caregivers are women, and many are aged 50 or older; on average, older care recipients are 75 years of age or more. Generally, caregivers provide 21 hours of care per week.[37,38]

Family caregivers, most of whom are spouses or adult children, form the backbone of community-based caregiving for older adults.[8] Caregiving may range from intermittent to round-the-clock care for individuals who are dependent on others to meet their daily personal care needs, illness-related care, and other supportive care, such as advocacy and steady companionship. Family caregiving can be equally as challenging as it is rewarding. Palliative care nursing includes attention to family situations and the consideration of the family in concert with the goals of care.

Nursing Interventions: Geriatric Palliative Care Nursing Practice

Numerous opportunities exist for the IDT and nurses specifically to proactively include palliative care in their daily practice. The goal of geriatric palliative care along the continuum of care in the community is to promote QOL and specialized care for older adults with serious illness regardless of the home setting.

Case Study: A Community-Living Older Patient (continued)

Soon after her hospitalization for heart failure, Mrs. Menendez was admitted to a community-based palliative care program. A comprehensive geriatric assessment, completed in the hospital was soon updated and the patient-family goals of care were reviewed. *Cor pulmonale*, a geriatric syndrome, emerged as a new diagnosis, and soon Mrs. Menendez's appetite diminished. Her medications were reviewed and distressing symptoms assessed. Upon consultation with Mrs. Menendez and her entire family, plans were put in motion to assure safe living conditions at home. Her bed was moved from the upstairs loft to the first floor. She was now close to the kitchen so that she could eat whenever and whatever she desired. Mrs. Menendez's social worker arranged for church members to bring in local homemade food during the week for Mr. and Mrs. Menendez, and they often stayed to chat for several hours. The palliative care team never visited in the afternoon so that Mrs. Menendez could continue to watch her favorite *telenovelas*. Family members pitched in to clean the house and maintain the yard. She now received Holy Communion on Sundays at home, which was arranged by the parish nurse and pastoral care team. Symptoms were well-managed, and she was now on morphine for dyspnea and an oxygen concentrator as needed. Her advance directives were completed in the hospital, and she desired to die at home, surrounded by family members. Mrs. Menendez's condition deteriorated, and she was admitted to hospice. Weekly patient–family and staff meetings were held to ensure that Mrs. Menendez's goals of care were being met. Soon after, Mrs. Menendez died peacefully at home, with all family members present.

Mrs. Menendez's case study illustrates key principles about geriatric palliative nursing care in the community and are illuminated in Box 38.4. Note that this overview does not take into account the substantive contributions of each IDT member, contributions that are critical in the home care environment. Additional considerations related to advocacy of older adult patients are provided.

Box 38.4 Summary of Geriatric Palliative Nursing Care in the Community

1. *Apply the principles of patient- (person-) and family-centered care.*
    a. A person-centered nursing approach embraces the whole person. Come to know the person as they are and craft a care plan to meet the patient–family goals of care that are realistic and measurable.
    b. Meeting basic needs is primary for all patients. Comprehensive care is necessary to support older adults in the community who require palliative care. Managing day-to-day physical and emotional needs can be taxing. A holistic palliative care approach in older adults includes attention to adequate and appropriate housing and living conditions, safety in all aspects of care (e.g., safe housing, daily life, medications), adequate food and nutrition, rest and sleep measures, the treatment of pain and discomfort, the management of functional decline, and maintaining cognitive reserve.
    c. Actively engage the older adult and significant others or family in education about their health and illnesses.
2. *Promote QOL and general well-being.*
    a. Physical assessment and management needs to be tailored to parameters for older adults.
        i. A comprehensive geriatric assessment (CGA) is necessary to distinguish age-related changes or differences related to disease pathology or medical conditions that may require intervention. The CGA is a multidisciplinary physical assessment and medical history approach that uses evidence-based tools and practice guidelines to capture the impact and needs related to medical condition(s), functional needs, and social and economic impact on the individual and constitutes a baseline assessment for care planning and future comparison.[39] Integrate palliative care assessment tools into the evaluation process.[40]
        ii. Recognize and differentiate normal age-associated changes from disease, geriatric syndromes, and atypical presentations. Monitor for increasing functional dependence in instrumental and general activities of daily living. Note the interrelatedness of medical conditions for complex palliative care management. Use the CGA and other symptom assessment tools to differentiate. Reduce harm and enhance efficacy by reviewing the medication profile routinely.
        iii. Monitor for the insidious predictors of emerging geriatric syndromes. Often obscure in the community, these conditions may increase risk and an accelerated decline. Note that the number, severity, and complexity of multimorbid conditions, geriatric syndromes, cognitive decline, and functional deficits require expert geriatric palliative nursing care.
        iv. Regularly anticipate and assess for distressing pain and symptoms using evidence-based tools for older adults. Dispel common myths of aging, such as pain is a normal consequence of aging.
    b. Continuous evaluation of mental health is necessary for older adults.
        i. Provide needed psychological support through the palliative care IDT or community resources.
        ii. Screen for depression and other psychological conditions as warranted using tools validated for older adults.
        iii. For people living alone, assess for loneliness and isolation that may affect safety and overall QOL. Work with IDT members to remediate and enhance social connections.
        iv. Identify and screen for loss and grief.
        v. Engage in positive communication skills.[28–30] Provide emotional support, therapeutic presence, and expert listening skills. Always instill hope.
    c. Assess and address spiritual needs and ways to enhance growth and fulfillment.
        i. Within the community context, learn about local formal religious organizations and social service agencies that may be faith-based and could be integrated into palliative care planning.

(*continued*)

Box 38.4 Continued

- ii. Collect information about community entities that can augment spiritual well-being, such as for breast cancer, grief, Alcoholics Anonymous, and caregiver support groups.
- iii. Identify congregational health ministries or parish nurses in the local community that interface services with palliative care teams.
- iv. Identify ways for the older adult to engage in creative or expressive arts, music, story-telling, and spiritual reminiscence.

3. Advocate for older adults.
   - a. Patient and family values and wishes guide the plan of care. Continuously ascertain individual and family preferences that may evolve over time. Identify cultural and spiritual backgrounds and values that can strengthen the care plan and support the older adult and family members.
   - b. Advance care planning is an expectation in palliative care.[41] Facilitate the documentation of advance directives and revisit frequently as the patient's condition changes.
     - i. Identifying terminal decline and prognostication can be problematic, but supporting the older adult patient along uncertain trajectories is imperative.
     - ii. Utilize ethical principles when discussing treatment complexity and feasibility when making clinical management decisions. Frame clinical management decisions within the context of risks, benefits, burdens, and prognosis related to life expectancy and QOL.[18]
     - iii. Elicit and attend to patient preferences in medical decision-making. Normalize advance care planning by assuring the older adult that preferences that are made known can and will be honored.
     - iv. Ascertain the dying preferences of the older adult patient should institutionalization emerge as a possibility. Discuss hospice early during care-planning.
   - c. Payment for services and healthcare may not be well understood. The patient and family may experience financial burden. Explore financial well-being and provide education and access to resources when indicated.
   - d. Identify and integrate community resources into the plan of care.
     - i. Facilitate the coordination of community services and referral networks.
     - ii. Navigating the complex fragmented health system can be overwhelming. Prepare for transitions and connect with community resources for needed or supplemental care at home.
     - iii. Ascertain formal and informal caregiving networks and supportive care services to enable the older adult to remain at home, should this be the goal. This may include housecleaning, home modification, transportation services, and more.
     - iv. Engage the palliative care IDT along the trajectory of the illness. Incorporate clinicians, support personnel, and others within the local and religious or social service community to augment the care plan.
     - v. Assess caregiver stress and burden and provide access to additional services as needed.[42] Promote positive communication, hope, and support.[43]
   - e. Complete a home evaluation assessment and ascertain ways to enhance safety (e.g., monitor fall risk). Assure that basic care needs are being met (e.g., food, clothing, housing). Secure community resources to meet identified needs (e.g., home-delivered meals programs, senior outreach services, home modification programs).

Conclusion

Aging is often not welcomed in today's society. Seen as a time of increasing disability, uncertainty, and numerous challenges, the trajectory of decline can be stressful and troubling for older adults and clinicians alike. However, it is does not have to be that way. Armed with knowledge and a skills set that is contextualized to meet the physical, psychological, social, and spiritual care needs of older adults, geriatric palliative care nursing can enhance and support the needs of older adults and their families. Community-based palliative care incorporates caring for the individual and the family within the context of where the person lives while fostering the principles of patient-centered care and advocacy. With this perspective, the possibilities of geriatric palliative care nursing in the community are endless.

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CHAPTER 39

Poor, Homeless, and Underserved Populations

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Key Points

- Poor people are at risk for a poor quality of living and a poor quality of dying.
- People whose lives have been filled with physical and emotional deprivation may be suspicious of efforts to engage them in "shared" decision-making to limit therapy, regardless of the therapy's burdens and limited benefits.
- Many persons who are poor have multimorbidities and other marginalizing social characteristics.
- Poor people's interactions with the healthcare system are frequently marked by rejection, shame, and discontinuity of care.

Introduction

Poverty is inextricably linked to increased morbidity, premature mortality, and limited access to both preventive healthcare and ongoing medical care. Beyond the medical outcomes of poverty, the personal and social costs are substantial and often invisible. People who are poor constitute a *vulnerable population*, a term used in community health to describe social groups at greater risk for adverse health outcomes. The root causes of this vulnerability typically are low socioeconomic status (SES) and a lack of access to resources.[1] Vulnerable populations by definition are underserved by the healthcare system in terms of access to and quality of healthcare. Underserved communities for palliative care include not just the poor and those without adequate health insurance but also the unbefriended elderly, non–English-speaking persons, the mentally ill, those with dementia, the developmentally delayed, nursing home residents, and those persons with limited health literacy.[2] When individuals or groups are denied what is regarded as standard-of-care interventions, moral questions about social justice must be asked.

The Institute of Medicine's report evaluating racial and ethnic disparities in healthcare failed to address the role of poverty in disparities.[3] However, the role of poverty in contributing to inequalities, independent of race and ethnicity, is difficult to decipher because class and race are often closely intertwined.[4,5] Some believe poverty may be most responsible for disparities in healthcare.[5] In a systematic review of social determinants of death in the United States, the researchers concluded that low education, poverty (at both the individual and community levels), racial segregation, limited social support, and income inequality were as likely causes of death as pathophysiological and behavioral causes.[6] In other words, being poor is as important a cause of mortality as are pathophysiological and behavioral explanations.

Although much has been written about the state of end-of-life (EOL) care in the United States, until recently not much has been said about those in our society who live at its margins, such as the urban poor.[7–16] Lewis (2011) conducted a systematic review of the barriers to accessing quality palliative care among the poor. Compared with those receiving palliative care who were not economically disadvantaged, the poor had less access to specialty care (often because of transportation), received fewer home visits and hospice services if they lived in high-crime areas, and were at higher risk of dying in institutions. Additionally, because of limited health literacy, more of the economically disadvantaged received more aggressive medical interventions, had fewer discussions clarifying goals of care, and were challenged negotiating complex care delivery systems.[17]

To be poor and to have a progressive, life-threatening illness presents more challenges than either one of these conditions alone. As Taipale elegantly notes, "Poverty means the opportunities and choices most basic to human development are denied."[18(p.54)] Consider the following questions: What type of death would a person hope for when that person doesn't have a home or lives in a room without a phone, a toilet, or kitchen? What are the meanings of life-threatening illness and death when premature death is an all-too-common part of life? What matters at the end of life if most of your life has been spent trying to survive day to day? These questions, in part, introduce us to the worlds of the poor who are confronting a life-threatening illness. Physical, psychological, and spiritual deprivation are not all that poor people contend with—deprivation also harms the moral self and the ability both to act and to live autonomously.[19]

The purpose of this chapter is to consider those characteristics of the poor as an underserved population that place them at risk when seriously ill and when palliative care is indicated.[4] In particular, this chapter looks at a subset of the poor who are homeless or marginally housed and how this affects both access to and quality of care at the end of life. This chapter focuses on persons whose "membership" in this group is more long term and not the result of an identifiable global economic crisis; similarly, this chapter does not address the experiences of persons living in extreme poverty in resource-limited countries around the globe.

The experience of being poor is not singular, nor it is universal; poor persons are as diverse a population as those who are not. Case studies are used to illustrate the concepts discussed and to demonstrate the need for more research to guide practice. The cases described were modified to disguise identifying characteristics; the cases are reflective of the authors' clinical practice in an urban area that is greatly impacted by homelessness.[20] Therefore, these cases are not generalizable to all the poor or all the homeless. Poverty is only one social determinant that affects health status and access to resources. Persons with many vulnerabilities (e.g., being poor and a member of a minority community, elderly, or having other medical problems) are at the greatest risk for adverse outcomes at the end of life.[21]

Epidemiology of Poverty in the United States

In 2016, more than 40.6 million Americans (12.7% of the population) were poor.[22] The poverty line established by the federal government is based on annual household income. In 2017, a single adult younger than 65 years of age was considered poor if his or her income was less than $12,060, and a family of four (with one adult and three children under age 18 years) was considered poor if their annual income was less than $24,600.[22] Most experts believe the federal definition of poverty underestimates the true prevalence of poverty in the United States. For example, the poverty line (annual household income) does not capture cost-of-living differences across the country nor out-of-pocket medical costs. Table 39.1 lists states in which the poverty level exceeded the national average in 2016.[23]

Table 39.1 States whose poverty rates exceeded the national average in 2016

State	Rate of poverty (%)
Mississippi	20.8
Louisiana	20.2
New Mexico	19.8
District of Columbia	18.6
Kentucky	18.5
West Virginia	17.9
Arkansas	17.2
Alabama	17.1
Arizona	16.4
Oklahoma	16.3
Georgia	16.0
Tennessee	15.8
Texas	15.6
North Carolina	15.4
South Carolina	15.3
Michigan	15.0
New York	14.7
Florida	14.7
Ohio	14.6
California	14.3
Idaho	14.4
Indiana	14.1

Source: From Reference 24.

The poverty rate has slowly been decreasing since 2014 from a rate of 14.8% to 12.7%; it is now approximately the same as just prior to the recession of 2008 (in 2007, the poverty rate was 12.5%).[24] High poverty rates continue due to continued high unemployment rates and the decreasing value of and access to public assistance; these issues are compounded by the increasing cost of healthcare, domestic abuse, mental illness, and drug addiction.[25]

Those living in poverty in the United States disproportionately include persons of color, children, foreign-born individuals, and single-parent families. African Americans have the highest rates of poverty in the United States (22.0%), followed by Hispanics (19.4%), Asians (10.1%), and non-Hispanic white (8.8%), according to the US Census Bureau Report for 2016.[24] Children have greater rates of poverty than young and middle-aged adults and the elderly. Approximately 42.1% of children under 18 years old living in a female-headed household were poor compared with 8.4% of children living with two married parents.[24]

Although poverty is not confined to urban areas, as evident in Table 39.1, which includes many states with large rural populations, 12.2% of the poor live in or near metropolitan cities.[24] Most of the poor have access to some type of housing or shelter, even if the basic accommodations (telephone, cooking and refrigeration, heat, water, private toilet, and bathing facilities) are inadequate. However, for a small subset, housing is marginal or unavailable. This subset is the focus of the following discussion.

Definition and Prevalence of Homelessness

Homelessness is defined in the Stewart McKinney Homeless Act as a condition under which persons "lack fixed, regular and adequate night-time residence" or reside in temporary housing such as shelters and welfare hotels.[25] Calculating the number of Americans homeless or marginally housed is extremely difficult. Most cross-sectional studies fail to capture persons transiently homeless—the hidden homeless, or those staying with family members, those living in cars or encampments, and others living in single-room occupancy hotels (SROs), sometimes known as *welfare hotels*.[26] Many of the poor and, in particular, the chronically homeless, avoid contact with social and health services, thus making the size of this population difficult to capture.

According to the National Coalition for the Homeless, on a given night in January 2016, 549,928 individuals were found to be homeless, and 40.6 million people experienced poverty over the course of that year.[25] Persons who are homeless are not members of a homogeneous group. Some are street people and chronically homeless, whereas others are homeless because of a financial crisis that put them out of stable housing. Street people may be more reluctant to accept services and may have much higher rates of concurrent substance abuse and mental illness (i.e., dual diagnoses).[27] Homeless persons frequently are veterans, victims of domestic violence, the mentally ill, and substance abusers. Although the rates of mental illness and substance abuse are higher in the homeless than among persons who are stably housed, assuming that all the poor or, for that matter, all the homeless suffer from these problems only contributes to stereotypes that fail to see the person who is before us. Domestic violence, mental illness, and substance abuse are not confined to the poor; while poverty does not cause these problems, poverty may well exacerbate them.

Health Problems Associated with Homelessness and Poverty

Those living in poverty tend to have more medical problems and decreased longevity than those who are not. In the United States between 2001 and 2014, higher income was associated with a longer life span, and the differences in life expectancy across income groups increased over time.[28] The gap in life expectancy between the richest and poorest 1% of the population was 14.6 years for men and 10.1 years for women.[28] There are several theories as to why this discrepancy in life expectancy exists. First, the poor likely have limited access to healthcare. Second, the poor tend to live in areas where the local environment negatively affects their health. Third, increased stress levels for the poor from lack of social cohesion negatively affect health. Finally, life expectancy is related to local labor market conditions.[28]

Interestingly, Chetty's study found that low-income individuals who live in highly educated cities live longer than similar individuals in lower educated cities. This suggests that city-wide public policies and/or living in close proximity to those with healthier habits has a positive impact on the poor. Geographic differences in life expectancy were significantly correlated with health behaviors, such as smoking.[28]

Numerous health problems are associated with homelessness. Many of these problems are related to environmental factors such as exposure to weather conditions, poorly ventilated spaces, unsafe hotels and street conditions, and high-crime neighborhoods where the poor are forced to live.[29] These health problems (Table 39.2) include malnutrition, lack of access to shelter and bathing facilities, problems related to drug and alcohol use, chronic medical conditions, chronic mental illness, and violence-related injuries.[26] One-fourth of the homeless have a major psychiatric illness; about one in three persons who are homeless abuse drugs and alcohol.[30] Drugs and alcohol are often used to self-medicate distressing psychiatric symptoms (e.g., anxiety, depression, post-traumatic stress disorder [PTSD]).

Table 39.2 Health problems common among the homeless

Causes	Manifestations
Malnutrition	Dental problems, tuberculosis, wasting
Lack of shelter and access to bathing facilities	Skin infections, lice, podiatric problems, hypothermia, tuberculosis, respiratory infections, sleep disorders
Drug and alcohol use	Overdose, seizures, delirium, infections transmitted through injection drug use or sex (such as HIV, hepatitis B, hepatitis C), trauma, falls, cirrhosis, heroin nephropathy, esophageal varices
Chronic mental illness	Paranoid ideation, antisocial behaviors, psychosis, suicide
Chronic medical conditions	Hypertension, arthritis, venous stasis ulcers, cellulitis
Violence-related injuries	Assaults, homicides, rape

Source: From Reference 26.

The individual effects of poverty on health status are irrefutable.[31] Consider the case of coronary artery disease (CAD): the link between onset of CAD and low SES has been established and is believed to be related to lifestyle factors such as poor dietary habits, tobacco use, and limited physical activity.[32,33] Poor cardiac outcomes among the underserved may also be related to limited access to standard medical care.[34] In Toronto, Canada, the homeless are five times more likely than non-homeless individuals to have heart disease.[35] In addition, the poor are twice as likely to have diabetes, 29 times more likely to have hepatitis C, and 4 times more likely to have cancer when compared with the general population.[35] The US national cancer registry of 2008 revealed that being poor was associated with being diagnosed with a more advanced disease stage and less aggressive treatment for individuals with breast, prostate, and colon cancer and with a higher mortality rate for those with breast and prostate cancer.[36]

A survey of the "hidden homeless" in Canada to identify housing, health, and social needs reported that, for many in the sample (aged 15–69 years), their first experience of homelessness occurred when they were in their teens.[26] Similar to other studies, most study participants were male, all had addiction problems, one-third had experienced violence in the prior 6 months, and about 25% reported avoiding being housed in shelters.[26] The medical problems most often cited were addiction, mental illness, dental problems, chronic pain, respiratory conditions, and sleep disorders.[26] Health and social needs identified included access to nutritious food, transportation, money management, addiction and mental health treatment, and healthcare services/providers that were respectful and not stigmatizing or demeaning.[26] Curiously, housing was not identified as a priority, perhaps in part because the researchers recruited most subjects from homeless service agencies that would have attempted to link services with housing.

In urban areas, healthcare services for the poor are often provided by public health departments, teaching hospitals, faith communities, and nongovernmental organizations—the so-called *safety net providers*. These services typically are overburdened and unable to meet the needs of the poor and the growing number of Americans who are uninsured who access them. For many of the poor, the emergency department (ED) has become the primary source of medical care.[10,37]

Where and How Homeless People Die

Limited data are available regarding the socioeconomic factors, places of death, and immediate causes of death of the homeless.[37] An important reminder for providers working with this population is the fact that "[h]omeless individuals have considerable experience with death and dying, and qualitative research has shown them to hold the expectation that their death will be both sudden and violent."[38] Similar to those who are not poor, most poor people die in institutions. For those who are homeless, dying on the street or in jail is also a fact of life.[39]

In the past, causes of death among the homeless included drug overdose; alcohol-related deaths; and hypothermia; accidents such as fires, falls, and pedestrian-motor vehicle accidents; and violent deaths related to homicide and suicide. Researchers in Boston analyzed mortality among the homeless for shifts in patterns from previous reports.[40] Electronic databases of a program that serves the homeless were searched along with the state death registry for causes of death noted on death certificates. For the 6-year study period (2003–2008), there were 1,302 deaths among the homeless.[40] Drug overdose was the leading cause of death, with opioids implicated in 81% of the drug-related deaths.[40] Younger homeless persons (25–44 years) were most likely to die of drug overdose.[40] In addition to opioids, 43% of drug-related deaths occurred in persons who were polysubstance users; alcohol was found in almost one-third of all drug overdoses.[40]

Heart disease and cancer (in particular trachea/bronchus/lung) were also significant causes of death in this population. Compared with matched adults in Massachusetts, the homeless aged 45–64 years, had a two- and threefold higher rate of death related to these chronic diseases.[40] Most of the deaths occurred in the hospital (53%) compared with community residence (27%) or nursing home (10%).[40] The demographic profile of the decedents was similar to past reports: male (81%), mean age 51 years (range 19–93), and white (60%).[40] Compared with prior studies, fewer homeless persons died of HIV disease; instead, drug overdose was the leading cause of mortality, and tobacco contributed to other potentially preventable chronic disease-related deaths.[40]

In light of all the contributing factors just explored, it is critical that palliative care interventions with homeless individuals are as tailor-made and specific as the interventions that better-resourced individuals have access to. Recognizing systemic inequities and continuing to consider social justice as a defining principle of quality palliative care allow application from a perspective that is person-first and equitable as a predominant characteristic. Best practices suggest palliative care for homeless individuals would be mobile (deliverable to people living in any location or situation), trauma-informed, and with an ongoing emphasis on harm reduction.[38]

Case Study: A Homeless Patient

Harold's referral to outpatient palliative care was ostensibly fairly straightforward: he was a 65-year-old Caucasian man with newly diagnosed high-grade bladder cancer, suspicious for bone and lung metastases, considering treatment options, with extreme pain. Upon closer inspection, however, some clear challenges immediately presented themselves: he had no phone or means of contacting him to arrange an appointment. The outpatient palliative care social worker found him in the urology clinic as he was having another appointment and escorted him to the outpatient palliative care clinic for his first visit.

Harold's life had recently changed dramatically. He had been homeless for 20 years and had made a living sorting recyclables. While dumpster diving the previous month, he had fallen and broken his hip. When he was taken to the hospital, it was discovered that, in addition to his broken hip, he had cancer. He became completely dependent on others for his activities of daily living. From the hospital, he received rehabilitation and physical therapy and moved into supportive housing with help from caregivers, meal delivery service, and case management. He was sorting through the rapid changes that had recently unfolded: his diagnosis, his change in housing status, and increased care needs.

Harold had an unusual intellect and story. He endorsed a significant trauma history: his mother was an alcoholic, and a desire to leave the abusive environment he had grown up in led him to join the military at a young age. He was able to complete some college under the GI bill and spoke fondly of his memories as an undergraduate. At no time, however, did he mention anyone he was close to or even in contact with. "I guess I have a hard time trusting people," he said. He was estranged from his only known living relative, a half-brother, and expressed no desire to reestablish contact with him. His life consisted of support staff, medical professionals, and his radio.

Harold was interested in completing an advance directive but posed a conundrum: he truly had no one to act as his proxy. Harold was more than willing to engage in conversations about his EOL preferences and even seemed to enjoy considering the theoretical outcomes of his choices and treatment course. When it came to choosing a person who could speak on his behalf, the only person he trusted was his case manager; she was unable to act as his decision-maker since she was part of his treatment team. Harold signed a physician order for life-sustaining treatment (POLST) and left his advance directive half-completed, filled in as much as he was able.

Poverty, Life-Threatening Illness, and Quality of Life

An enormous body of evidence has demonstrated health inequities related to race and ethnicity; indeed, eliminating health disparities has been a federal policy priority.[3,37] Understanding the role race and ethnicity play in the EOL experience of the urban poor, however, is complex, in no small part because, as Crawley observed, race and ethnicity have been conflated with SES.[41–43] For the purposes of this chapter a more focused review of the literature is presented without attempting to untangle the role of race/ethnicity from SES in explaining the poorer outcomes such as quality of life (QOL).

In a systematic review of the incidence, treatment, and mortality related to heart failure and SES, the researchers evaluated 28 studies that met inclusion criteria. The review concluded that disadvantaged persons had increased incidence of heart failure, higher rates of admissions and rehospitalizations, inconsistent use of beta blockers for treatment, and overall higher mortality rates than their comparison groups who were more advantaged.[44]

Solid organ transplantation is standard of care for end-stage organ diseases that would otherwise compromise QOL and shorten survival. The literature has documented disparities among racial and ethnic minorities related to both access to organs and poorer graft outcomes for those who receive organs.[45,46] Risk factors for poorly functioning kidney grafts match the profile of the urban poor: African American, male, older age, unmarried, unemployed, low income, living in poor neighborhoods, and geographic distance from transplant center.[45] Lacking a kidney transplant, for example, results in a person with end-stage renal disease (ESRD) being required to transport themselves to the dialysis center (if poor, this usually means on bus or on foot) and endure lengthy, uncomfortable hemodialysis treatments usually three times a week, indefinitely. This kidney function replacement therapy surely compromises the QOL.

Poor people endure a heavier burden of cancer according to several reports from the American Cancer Society and other researchers.[47] In a special report on cancer disparities and premature deaths, the American Cancer Society stated categorically that poverty was responsible for cancer disparities and premature cancer deaths regardless of race/ethnicity.[48] Edwards and colleagues used a community-based participatory research design to understand the factors that impact cancer disparities in East and Central Harlem compared with more affluent neighborhoods of New York City.[47] Forty study participants' interviews uncovered a number of themes. Many of those interviewed in Harlem believed information needs were vast and included available community resources, prevention and early detection of cancer, accessing cancer care, and symptom management. Additional themes that impacted cancer disparities in their community included unmet support needs that allowed discussion of cancer's impact and ways to cope, secrecy about the diagnosis, mistrust of healthcare systems, and strongly held beliefs of stigma, fear, and fatalism. Generally, poor people encounter substantial barriers to obtaining quality cancer care, present with more advanced disease, experience more pain and suffering, and are more likely to die earlier of cancer than their economically advantaged counterparts.[48] In addition, patients without insurance were found to have more advanced disease, pursue fewer treatments, and worse survival rates.[49] Findings of the impact of poverty on cancer care are summarized in Box 39.1.

Box 39.1 Poverty and Cancer

- Poor people lacking access to quality healthcare are more likely to die of cancer than non-poor people.
- Poor people experience greater cancer-related pain and suffering.
- Poor people facing significant barriers to getting health insurance often do not seek necessary care if they are unable to pay for it.
- Poor people and their families make extraordinary sacrifices to obtain and pay for care.
- Poor people lack knowledge of available community resources, lifestyle factors that contribute to poorer health outcomes, warning signs of cancer, symptom management strategies, and how to access follow-up cancer care.
- Psychosocial support, both individual and group, and outreach efforts at the community level are lacking.
- Mistrust of healthcare professionals, teaching hospitals, and researchers is common and a barrier to care-seeking.
- Fatalism, fear, and stigma about cancer are commonly held beliefs that prevent accessing care.
- Secrecy about cancer interferes with accessing care that may even be available in the nearby community.
- Cultural barriers between healthcare professionals and the community may result in services that do not take into account the community's needs, including health literacy. Many in impoverished neighborhoods are certain that environmental pollution may contribute to cancer rates.

Source: Adapted from References 5 and 47.

Barnato and colleagues conducted a national telephone/mail survey of community-dwelling Medicare beneficiaries to explore racial and ethnic differences regarding preferences for and concerns about EOL treatment.[50] The sample of 2,847 adults included 2,105 whites (non-Hispanic), 489 blacks (17.4%), and 113 Hispanics (4%).[50] When most subjects were asked about their preferences if they were diagnosed with terminal illness with less than 1 year to live, the responses were quite similar: to die at home, without life-prolonging medications with adverse effects, and without mechanical ventilation if such treatment extended life by 1 week to 1 month. However, compared with white respondents, minority subjects were more likely to prefer more medical interventions, including dying in the hospital, possible life-extending medications regardless of their side effects, and mechanical ventilation for 1 month or 1 week.[50]

In the ethnographic study *Dancing with Broken Bones: Portraits of Death and Dying Among Inner-City Poor*, Moller (2004) poignantly recounts and photographically documents the stories of poor patients followed by an oncology clinic in a Midwest city. His insights about the suffering of the urban poor are profound: "the dying poor are the quintessential violators of the American dream; they live in the shame of poverty and with the unpleasantness of dying."[10(p.10)] Because much of a person's worth in American society is connected with social status indicators such as occupation, income, and home ownership, the poor represent those who have not made it, have not lived up to their potential. Being poor then becomes a matter of personal failure rather than a social problem requiring public policy changes.[51] From Moller's longitudinal qualitative study of poor inner-city patients, their families, and their healthcare providers, the researcher drew a number of conclusions, which are listed in Box 39.2. His work can perhaps be summed up by saying that the indignities of being poor in America are only intensified when that person is also dying. Unlike persons who are not poor, dying is not always feared in the same way because, for some persons who are socially

Box 39.2 Insights about the Dying Poor

- Poverty inflicts substantial harm throughout life.
- Poverty exacerbates indignity and suffering throughout dying.
- Patients/families are often mistrustful and angry about the care received.
- Patients may, at the same time, be grateful for the care received.
- Spirituality plays an important role in providing strength and resilience when dying.
- Social isolation increases suffering.
- Hidden and sometimes unexpected sources of support can emerge from family and community.
- The emergency room is the front door to healthcare.
- The organization of medical care is frequently fragmented and lacks continuity.
- Funerals are important rituals, and their cost creates enormous stress for survivors.

Source: Adapted Reference 10.

or economically disadvantaged, dying may represent freedom from the misery of living.[10]

Clinical Presentations of Advanced Disease in the Poor

Persons who are poor frequently present with advanced disease, in part related to delays in diagnosis, mistrust of healthcare systems, and late discussions of advance directives and EOL care options.[52] In addition to the late-stage disease presentation, many have significant comorbidities that affect both the palliation of symptoms and the course and treatment of underlying illnesses. These clinical management issues usually occur within the context of complex psychosocial situations, as the following case illustrates.

Case Study: Dying Poor

Mary was a 55-year-old homeless African American woman with an extensive smoking history and substance abuse disorder who was diagnosed with metastatic lung cancer during a brief hospitalization. She was discharged to a local shelter and had been scheduled to follow up with the oncology and palliative care services as an outpatient. Mary did not make it to either of these appointments. Multiple attempts were made to contact her and reschedule, but with a full voicemail inbox, there was no way to leave her messages. Contact was made with Mary's mother, who refused to relay any messages to the patient.

Mary was not seen again until she presented to the hospital for dyspnea and pain about a month later. When she was discharged the second time, social work had arranged for Mary to stay at Medical Respite, a facility that offers specialized healthcare services and temporary housing to homeless patients. With the support from Medical Respite, Mary made it to her next appointment, palliative care. Mary made it abundantly clear that her goals were to seek treatment. Her main way of coping with her illness was by avoidance. She valued direct communication but often struggled with self-regulation and was prone to emotional outbursts. Unfortunately, Mary assaulted a fellow resident at Medical Respite and was discharged back to the streets before she was able to attend her oncology appointment. Repeated attempts were made to have Mary follow-up with oncology so she could get started with treatment, but she never made it to the clinic.

Mary was intermittently living on the streets and with friends. Her drug use made it challenging for her to attend regular appointments and complicated her pain management. At one point, transitioning to inpatient hospice was discussed; this would enable Mary to have access to housing and consistent symptom management, but she declined, mostly because she valued her freedom and didn't want to give up her dog, who was not allowed in the facility.

Mary intermittently presented to palliative care but was ultimately lost to follow-up for about 6 months. During this time, Mary did her best to get her chaotic life back in order. When she re-presented to palliative care, she was very proud to share that she had independently secured a room in a SRO and was seeing a new doctor at a public health clinic who was helping to manage her pain. Mary expressed the desire to be re-engaged in care and seek cancer-directed therapies. It wasn't until after her sixth hospitalization, approximately 14 months after her initial diagnosis, that she finally started palliative immunotherapy. During restaging, it was found that Mary's disease had progressed, and she had developed brain metastases. Her oncologist was planning to share this with her at their next appointment; however Mary was urgently admitted to the hospital for esophageal stricture that required stenting. Unfortunately, while Mary was being consented for this procedure, the gastroenterologist, unaware that the patient had yet to be been informed, disclosed the fact that she now had brain metastases. Mary's fragile world crumbled. She felt like her providers had purposely misled her, further complicating her fractured relationship with the medical system.

It was during this last hospitalization that Mary's body began to decline, her respiratory status worsened, and she became delirious. Mary admitted that her body was starting to fail; "I feel I'm coming to a stage . . . I don't want to think about it. . . . My body is changing." While her oncologist hoped that she would have a good response to the immunotherapy, it was too late. Mary became bed-bound and unable to care for herself; she ultimately decided to return to her apartment for home hospice. Mary died only 1 week later, just 4 weeks after her one and only dose of immunotherapy.

For many persons who are poor or lacking adequate health insurance, access to treatment is a significant factor that influences symptom management.[53,54] For example, if an antiemetic prescribed to relieve the recurrent nausea experienced by a poor person with hepatocellular cancer is not covered on the Medicaid formulary or the person is not eligible for any drug-assistance program, then the range of medications used to manage the nausea is limited. The newest high-tech strategies or methods to control symptoms are not an option for the person who lives in a tent encampment with no access to running water or electricity. Most poor persons are institutionalized to manage uncontrolled symptoms and to provide both chronic and terminal care that cannot be managed sufficiently on the street or in the shelter.[10] The management of symptoms associated with progressive illness is further complicated by end-organ diseases, such as liver or renal disease, that may alter the pharmacokinetics of medications used to palliate symptoms.[6] Determining whether a patient is experiencing an adverse drug reaction is not easy when the person has multimorbidities, has rapidly progressive disease, is malnourished, is detached from his or her body as a coping strategy from a history of trauma, or may be continuing to use alcohol or other substances.

Comorbidities also affect the healthcare providers' ability to realistically estimate prognosis and the nature of symptoms or problems that might occur down the road. Charting the dying trajectory for the chronic progressive illness may be conceivable, but superimposing the other illnesses and injuries that the very poor live with and manage creates jagged peaks and valleys in a downward course. How quickly the life-threatening illness will progress becomes a prognostication puzzle; some persons who have been living on the street truly seem to have had nine lives. On the other hand, despite the prevalence of substance abuse among the poor, lack of attention to self-care activities cannot be assumed in all drug users. Race, class, and housing status cannot be used as surrogate predictors of who abuses drugs and alcohol or who will adhere or not adhere to treatment demands.[55,56]

Case Study: An Alcoholic Patient in Detox

Adam was in the hospital for 3 weeks detoxing from life-long alcohol abuse before he could receive treatment for his liver cancer. “I can’t not drink,” he told his team. He started drinking when he was 12 years old and self-disclosed a multisubstance suicide attempt at 16, when he found a medicine cabinet full of benzodiazepines and washed a handful down with a glass of vodka. Compared to many patients, he was relatively well-monitored, and, during a routine 3-month abdominal scan for his liver disease, his doctors saw hepatocellular carcinoma. When he came to the hospital for his radiofrequency ablation treatment, he needed to be on high doses of lorazepam to mitigate the risk that he would seize as he had in the past when he attempted to stop drinking. Following his surgery, the inpatient palliative care team was consulted because he had articulated suicidal ideations and substantial pain in his abdomen. Adam was a stocky 39-year-old Caucasian man, his arms and chest were covered in an array of mismatched tattoos, and when he smiled, he revealed a mouth full of missing teeth. “I feel like I’m in jail,” he said of being inpatient in the hospital.

Adam quickly told the inpatient palliative care team about his life. He grew up on a farm in Ohio, and he had four children he barely knew because he had been incarcerated for much of their young lives. He missed his family and the goats he grew up taking care of, and he wanted very much to reconnect with his family. He also told the inpatient team that he was in tremendous pain that was being undertreated because the team was concerned about his mental status. His capacity would wax and wane, he could rarely recall specifics of conversations from even one day prior, but his desire to reconnect with his family stayed constant.

When Adam came to the outpatient clinic, he was accompanied by staff from Medical Respite, where he was living and recovering from his treatments. He was a known entity to them, however, from his many stays at the sobering center located on one side of the building: the sobering center social worker was listed as one of his emergency contacts. He requested that his outpatient appointments be scheduled early in the morning so he could make attempts to abstain from drinking beforehand. Even with these efforts, he would frequently come to appointments intoxicated, having needed a drink to steady his nerves, and smelling of urine.

As the outpatient team continued to engage Adam about his goals, reconnecting with his family remained his top priority. He would sporadically come to his outpatient appointments, often missing them because he was rehospitalized following falls and other injuries he sustained while intoxicated. He declined substance abuse referrals, mental health treatment, and assistance with housing. Together with the sobering center social worker, many attempts were made to contact his family; ultimately, his family declined to reconnect with him.

Barriers and Challenges to Providing Palliative Care

As suggested, there are many barriers (structural or community factors) that limit access to quality palliative care for the urban poor and an equal number of challenges (individual and illness-related factors) that are common among the urban poor with advanced disease.[10]

Barriers that influence the health status of anyone living in an inner city include high rates of violent crime and drug use; marginal or substandard housing; limited public transportation; convenience stores that sell more tobacco and alcohol than fresh fruits and vegetables; environmental pollution; oversubscribed and often charity-dependent community health services, if even available; lack of pharmacies and/or restricted drug formularies; and lack of insurance or a reliable income source to meet basic needs.[14,57,58]

Challenges to providing palliative care to the urban poor with advanced disease include person-specific or illness-related factors, summarized in Table 39.3. Illness-related challenges include the prevalence of serious mental illness, addiction, and

Table 39.3 Psychosocial challenges in providing palliative care to the urban poor with serious illness

Illness related	Prevalence of concurrent mental illness and substance abuse
	Decisional incapacity; presentation with advanced disease
	Multiple comorbidities
	End-organ diseases altering pharmacodynamics
Resource challenges	Health literacy
	Family or friend caregiver availability
	Lack of/need for designated health proxy/agent in the event of decisional incapacity
	Chaotic lives that have little space for day-to-day illness demands
	Limited ongoing therapeutic relationships with health or social service providers
	Survival or addiction may overshadow illness management
	Competing role responsibilities
	Functional impairments, geographic distances, and transportation limitation compromise appointment keeping
Relationships with healthcare system or providers	Cultural history of racism, discrimination, or rejection in healthcare system
	As a result of disrespectful, rude, or dismissive interactions in past, may present as angry, avoidant, suspicious, or nonadherent with care recommendations
	Healthcare providers often have different cultural and ethnic backgrounds/worldviews
End-of-life preferences	Reluctance to relinquish aggressive medical management
	Different assumptions about optimal end-of-life care, particularly in communities of color
	Lack of advance care planning because life is experienced moment to moment
	Tendency to equate goals of care modification with abandonment or continued poor care
	Spirituality may be a hidden resource for comfort and in guiding decision-making

Source: From Reference 2; reprinted with permission of Hospice and Palliative Nursing Association.

PTSD; multiple comorbidities including end-organ disease and other chronic diseases; and presenting for care with advanced disease that may be less responsive to disease-modifying interventions even were such therapies available. Social resource challenges include fragile support systems, health literacy concerns, need for a healthcare proxy or agent if a family member or friend is not available, and chaotic lives in which survival frequently overshadows illness management.[59–61] Relationships with healthcare providers and systems may be frayed if they do exist, and providers may come with quite different worldviews and cultural backgrounds than the person presenting for care. In general, the barriers to providing quality palliative care to this population require community level or policy interventions, while some of the challenges noted require person-centered interventions. Both levels of approaches will be discussed following a review of the evidence base for providing palliative care to the urban poor.

Research from Kayser demonstrates five regularly occurring barriers that were found when delivering palliative care to those living in inner-city communities. First, an absence of family support; second, communication barriers with healthcare professionals; third, minority stress; fourth, caregiver burden; and, finally, a lack of spiritual support.[62] *Minority stress* is described as chronically high levels of stress faced by members of stigmatized minority groups.[63] Minority stress often enhances vulnerability, leading to isolation which in turn impedes development of trust. These themes demonstrate the paramount importance of an interdisciplinary team and culturally sensitive support.

Mistrust can come from many directions. Not only can patients have inherent distrust of authority-based institutions, but healthcare providers were also found to be distrustful of the underserved population.[63] This is further supported by Håkanson, whose research found that, in addition to the barriers felt by the healthcare provider, including lack of a fixed residence, mental illness, substance abuse, difficulty adhering to treatment recommendations, and lack of follow-up, the homeless patient felt that their healthcare provider often lacked adequate understanding or respect of their circumstances and related care needs.[64]

Evidence-Based Palliative Care for the Urban Poor

The evidence base to guide palliative care for the urban poor is sparse and includes reviews, program evaluations, and research that used both descriptive and clinical trial designs. The reviews were found in textbooks and journal articles.[8,17,65] The program evaluations described shelter-based, home care palliative care programs and the impact of hospital-based palliative care consultation services on family satisfaction and do-not-resuscitate (DNR) status.[66–68] Researchers used in-depth individual and group interviews, surveys, and clinical trial approaches. Researchers explored attitudes and beliefs about EOL care[11,12,69] and barriers to palliative care among low-income cancer patients,[14] tested methods for promoting advance directive completion among this population using low-literacy versions[70] or other methods,[15] and described the experiences of the urban poor with advanced disease who were community dwelling or in a dedicated AIDS nursing home unit[9] and the hopes and concerns about care at the end of life for inpatients with serious illness at a public hospital.[13]

Of the available "evidence" evaluated, only advance care planning using a fifth-grade reading level version or other methods including one-to-one coaching or independent self-completion was of a sufficient quality to support its translation into practice.[15,69,70]

Clinical Interventions and Community/Policy-Level Approaches

Clinical Interventions: Importance of Relationships

Developing trusting therapeutic relationships is at the very heart of all clinical interventions regardless of whether the person is impoverished and marginally housed or has social and financial resources. Therapeutic relationships take on a particular salience with those facing serious illness and death. However, developing trusting relationships with persons who have experienced rejection, abandonment, or felt unwelcomed in healthcare settings requires patience and time—scarce resources in busy clinical settings. Moreover, some groups seeking medical care may value and trust relationships more highly than data-driven guidelines,[71] thus increasing the importance of patient-centered, culturally sensitive palliative care.

Multiple qualitative studies of the urban poor with serious illness have demonstrated a desire for therapeutic relationships with healthcare professionals characterized by respect, by "sitting down and listening," and by honesty and consistency.[9,13,69,72] When patients and providers come from different life experiences, the most basic principles of therapeutic communication are crucial (see Box 39.3 for suggestions). These include addressing the person formally unless given permission to use the familiarity of first names, sitting at eye level when interacting, and appreciating that the palliative care philosophy and principles guiding care approach may be quite foreign or even suspect as a means of denying care (again) or as an "ethically charged" clinical intervention.[65,71]

Davis and colleagues interviewed homeless chronically ill adults about the case management services they received to stabilize their medical conditions and social situations.[72] Four themes emerged from the interview data: (1) participants described profound isolation prior to receiving case management services, (2) caring relationships with case managers were key to the program's benefit, (3) case managers assisted participants to navigate medical and social service systems, and (4) participants perceived improved health because of the interpersonal and practical interventions. The title of the study report perhaps says it all, "Because Somebody Cared About It. That's How It Changed Things."[72]

Assessment Considerations

A comprehensive assessment by a nurse includes history of illness, treatment, comorbidities, medication, self-care abilities, symptom management, a physical examination appropriate to the presenting complaint and history, and psychosocial information that may shape EOL care options. Obtaining psychosocial information over time, rather than in a single session, is more likely to promote a therapeutic connection and to uncover a richer narrative. Admittedly, appointment follow-up difficulties often justify trying to get as much information as possible during an

Box 39.3 Helpful Suggestions when Engaging a Difficult-to-Engage Client

- Address anyone older than 40 years of age by the title of Mr. or Ms. Ask permission to be on a first-name basis.
- Do not hesitate to shake hands.
- Be prepared to meet people who are more intelligent, more perceptive, and more wounded than you expect.
- Be tolerant. How would you react if you were in that situation?
- Don't make promises you can't keep.
- Don't take it personally.
- Taking time out helps prevent burnout.
- Get to know the community.
- If you feel you have to save the human race, do it one person at a time.
- Providing material assistance (e.g., clean socks, food, hygiene kits, taxi vouchers) opens people up.
- Usually the most difficult clients are those most in need. Throw the words "noncompliant" and "nonadherent" out of your vocabulary.
- Make eye contact. If the person does not like eye contact or becomes agitated, avoid using it.
- Keep in mind that people who live intense lives may not particularly like unasked-for physical contact.
- Don't be afraid to ask "stupid" questions; patients' answers are better than your assumptions.
- Adjust your expectations and accept small victories with satisfaction.

Source: From Reference 73.

Box 39.4 Recommended Areas to Cover during the Psychosocial Assessment

- *Housing*: Where do you usually stay at night?
- *Food*: Are there times when you are hungry from not having enough to eat?
- *Transportation*: How do you get to appointments or to the hospital?
- *Income*: Are you receiving any income or benefits?
- *Preferred communication methods*: How can we get in touch with you?
- *Caregiver availability*: Is there someone you can count on when you need help?
- *Use of other resources*: Do you have a case manager, peer advocate, sponsor, or patient navigator?
- *Literacy*: Are you much of a reader? How do you like to get information about your health?
- *Spirituality*: What role does faith or religion play in your life?
- *Cultural identity*: What beliefs or practices about health and healing are important for us to incorporate into your care?
- *Safety*: Do you feel safe where you're staying?
- *Coping resources*: How have you coped in the past when dealing with challenges?
- *Substance use*: Have you used alcohol or drugs to cope? If so, what difficulties have their use presented in your life?

initial encounter. While various screening or assessment tools for specific aspects of care are available and recommended in many practice guidelines, the timing of when, or whether, to use such standardized instruments needs to be evaluated on a case-by-case basis in a population that may be more hesitant to engage in care and suspicious of how this information may be used. See Box 39.4 for suggested questions[73] to include in the psychosocial assessment.

In addition to the interpersonal interventions to engage the client in a therapeutic interaction, nurses are often required to become knowledgeable about the availability of services provided by community agencies. Are pharmacies available, what are their hours, are they willing to accept telephone orders, and what medications are kept on hand? What supportive services are available, such as food/meal programs, case management services, representative payee programs, supportive housing, and crisis mental health and substance abuse programs? What home health or hospice program serves the community, and are there any restrictions on services because of concerns related to staff safety?

Knowing which agencies or services are involved with a client and communicating with them assures consistency of approach and continuity of care. Advocacy is often required to access services such as pain management, substance abuse treatment, mental health services, and social services for housing and money management. Being a steady, knowledgeable, and dependable presence in a marginalized person's life can be a quick road to building trust and rapport.

In summary, developing therapeutic relationships with the poor and homeless requires (1) expecting the person's trust to be earned over time (sometimes a long time) and not taking it for granted; (2) respecting the person's humanity, no matter how they look, what they say, and what feelings they evoke in us; (3) appreciating the person's unique story as influencing his or her response to illness and death; and, finally, (4) recognizing and addressing maladaptive behaviors.

Providing Palliative Care to LGBTQIA Individuals

Gender presentation and sexuality are additional factors that contribute both to homelessness and to accessing palliative care. According to a 2012 Gallup poll, one in five lesbian, gay, bisexual, transgender, queer/questioning, intersex, allies (LGBTQIA) people who live alone live at or under the federal poverty level.[74] The Annual Homeless Assessment Report states that "fewer than one percent (1,770) [of homeless individuals] are transgender."[75] It is known that transgender individuals are more likely to experience homelessness than are gender-conforming individuals, as well as other more blatant and disguised forms of discrimination and oppression.[76,77]

Based on previous experiences with healthcare providers and judgment, LGBTQIA individuals can be distrustful of healthcare providers, fearing judgment of who they are, their economic and employment histories, and their partners and "chosen families."[76,78] Previous generations' experiences of marriage discrimination created challenges in allowing LGBTQIA individuals' partners to assume next-of-kin status, and although we have made national strides in the area of marriage equality, the scars of prejudice still inform the fear and mistrust some LGBTQIA individuals have of the medical system: 20% of LGBTQIA individuals report not disclosing their gender and sexuality to their healthcare providers.[76,77]

As mentioned, many homeless individuals move into institutionalized environments at the end of their lives. Due to previous stigmatization and fear of emotional retribution or abuse, some transgender homeless individuals may choose to "detransition" as opposed to living their final days in the gender they feel themselves to be.[78–80] The choice to "detransition" for safety and acceptance is personal and can be deeply destabilizing and traumatic. It reminds us of the impossible choices associated with EOL needs in marginalized populations: treatment or housing? Identity or care?

Case Study: A Transgender Patient

Adele was a 54-year-old transgender male-to-female patient with human papillomavirus-related oropharyngeal squamous cell carcinoma. She had a history of methamphetamine abuse and sex work, was extremely distrustful of medical providers, and feared physical exams. Advance care planning with her was a challenge: she was estranged from her family, had few friends and limited support, and, in her own words, "[w]hen I don't know what's coming, I bolt."

Initially, Adele sought treatment for her cancer, but she needed to stop radiation after only one session due to claustrophobia and paranoia brought on by the restraints required. Additionally, her treatment was complicated by her nutritional and mental health needs. Before receiving chemotherapy, it was clear that she needed improved nutritional status, and she was amenable to and accepting of a percutaneous endoscopic gastrostomy (PEG) tube for additional nutrition. Shortly after receiving the PEG tube, however, she had a psychotic episode, requiring full physical and pharmacological restraints. She stated that she struggled to recognize her body with the PEG tube in it. In the hospital, surgical teams were concerned about her ability to heal should she pull out the PEG tube as she said she planned to.

Ultimately, with the support of medical ethics, surgery, oncology, and medicine teams, Adele was supported in removing her PEG tube and continuing to eat by mouth. There were many other challenges along the way: she insisted she needed to leave the hospital to smoke cigarettes, receive her monthly supplemental security income check, and connect with her dog—all reasonable desires, but again underlining the emphasis placed on immediate needs versus long-term health goals.

Much effort was made to engage Adele in care. Her circle of support, largely comprising community case managers, was brought to the hospital to contextualize her experience. She was briefly placed at a long-term care institution, but left after a few weeks, absconding on a day pass and never returning. She re-presented at the county emergency department and was admitted to the hospital with complaints of both abdominal pain and difficulty breathing, requiring another prolonged hospitalization. With much effort, she obtained emergency housing at a SRO with assistance from both an outpatient hospice agency and case management services. With support of hospice, she was able to live independently, focusing on her goals and desires, and ultimately died in an inpatient hospice facility. The hospice team was unable to contact her family.

Adele's story reminds us of a variety of factors that can complicate care both for gender nonconforming and impoverished individuals, and the intersectionality of these two populations. Her articulated distrust of the medical community, shifting goals between QOL and curative cancer treatment, and emphasis on immediate needs as opposed to long-term care planning made plotting a course trajectory with her a near impossibility. Part of working with Adele meant allowing her to feel she was in control; empowering her to make choices, even ones providers did not necessarily agree with; and managing provider expectations and distress around her choices.

Program-, Community-, or Policy-Level Approaches

While there are no clinical practice guidelines developed specifically to define palliative care of the underserved, *Clinical Practice Guidelines for Quality Palliative Care* does serve as a useful framework for developing and evaluating services to meet the unique needs of these populations.[81] In particular, preferred practices addressing social aspects of care; spiritual, religious, and existential aspects of care; and cultural aspects of care can be used to shape program development and service evaluation.

Two programs designed to meet the palliative care of the poor, one home-care based program in Hawaii[66] and the other a shelter-based program in Canada,[82] documented cost savings and favorable results for other quality indicators. These may serve as models for other communities with different needs and resources to consider in program development. Additionally, palliative care services in safety net hospitals have demonstrated improved family satisfaction and increased the likelihood of patients/surrogate decision-makers agreeing to DNR status when the patient is seriously ill and unlikely to survive this intervention.[67,68]

Obviously, at policy and community levels, stable housing is critical to providing a decent QOL for any human being. Researchers noted the benefits of supportive housing to minority elders in East Harlem, including better psychological outcomes and increased use of informal supports,[83] and to persons who were chronically homeless with severe alcohol problems in Seattle, which demonstrated cost savings.[84] Housing First is a policy advocated by advocates for the homeless and by professionals caring for them as the initial step in turning around the lives and hopefully preventing the premature deaths of those who are without a home (http://www.endhomelessness.org/pages/housing_first). Advocating for housing for the urban poor and those who are homeless is as critical as advocating for preventive care, chronic disease management, symptom management, the opportunities to articulate wishes about

EOL care, spiritual care, and for mental health and addiction services. Without safe housing, the opportunities for a good enough death may not be possible.

Several scholars have argued regarding the social justice implications of palliative and EOL care. Crawley noted that within the African American community premature deaths have been associated with both individual and institutional injustices.[85,86] Racism, discrimination and health disparities, and research abuses such as the Tuskegee syphilis study have betrayed the trust of many African Americans and in part explained the determination among some to "go down fighting" rather than embrace some notion of a good death. A provocative essayist, Krakauer warned that advocating for palliative care in situations where disease-modifying therapies are standard of care for resourced communities or countries was unjust, unacceptable, and perhaps unethical.[87] His argument was based on concerns about global efforts to offer palliative care to persons suffering with cancer or HIV disease because the costs of disease therapies were exorbitant and unattainable by resource-strapped developing economies. The same argument could be made for the poor in the United States. Palliative care should not be promoted as a substitute for society's failure to provide all Americans, rich and poor alike, with their basic needs for food, clothing, shelter, education, employment, community, or promising futures. In that way, palliative care must be part of a healthcare system and social contract that includes indicators of socioeconomic well-being alongside safe environments, food and shelter, meaningful employment, support for families and communities, health promotion, disease prevention, chronic disease management, and palliative care.

Conclusion

Providing palliative care to the poor, especially the homeless, is extremely challenging. Comorbid illnesses, illnesses associated with poverty, and clarifying the etiology of presenting symptoms may seem almost impossible at times. Psychosocial risk factors and strained relationships with healthcare providers sometimes result in the client receiving futile or unwanted medical interventions at an advanced stage of illness. Clarifying with a patient what constitutes a good death for him or her can be humbling when the patient tells you he or she wants simply to have shelter and to feel safe. Meeting the palliative care needs of this underserved population will require innovative practice and education models. To truly improve EOL care for the poor, nurses need to advocate for public policies that assure access to safe and stable housing, health insurance, and client-centered, community-based primary care.

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CHAPTER 40

Palliative Care for Patients with Mental Illness

John D. Chovan and Betty D. Morgan

Key Points

- Persons with severe and persistent mental illness (SMPI) die 10–25 years prematurely, and the majority die from chronic, life-threatening physical illnesses such as cancer, heart disease, chronic obstructive pulmonary disease (COPD), and dementia.
- Enhanced communication skills with an emphasis on therapeutic communication are needed to work with patients with SPMI.
- Ethical issues, including determination of capacity and competence, may arise when working with people with SPMI. Simply having a diagnosis of an SPMI, however, does not necessarily indicate lack of capacity or competence.
- Redefinition of family may need to take place in order to include the patient's support system in his or her care.
- Consultation and collaboration are essential to care for the population of people with SPMI to meet the needs of patients and their support systems.

Introduction

Severe and persistent mental illness (SPMI) is a classification of mental disorders characterized by serious functional impairment that interfere greatly with or limits one or more major life activities, such as self-care, independent living, interpersonal relationships, and ability to work or go to school. SMPIs include recurrent major depressive disorder, bipolar disorder, thought disorders—such as schizophrenia spectrum disorders and delusional disorders—and the personality disorders. An estimated 43.4 million adults (approximately 17.9%) in the United States were living with mental illness in 2015. A smaller number of people, 9.8 million adults or approximately 4% of Americans (1 in 25) live with an SPMI.[1] Among sexual minority adults, 3.9 million Americans had a diagnosis of mental illness, 1.4 million of which (24.3%) were living with SPMI. These percentages were greater than those among sexual majority adults.[2]

Comorbidity is common; almost half of the people who are diagnosed with a mental disorder meet criteria for a second mental disorder, with mood, anxiety, and substance use disorders being the most common comorbid mental illnesses.[3] The Global Burden of Disease study presented data revealing that mental illness accounted for the largest percentage (7.4%) of all disease-adjusted life years that measure disease burden.[4]

People with SPMI reportedly die 10–25 years earlier than the general population worldwide.[5] The increase in mortality has been associated with cardiovascular and respiratory diseases, suicide, and accidental death by alcohol or other drugs.[6] Comorbid medical illnesses that are commonly observed in those with SPMI include hypertension, cardiac disease, diabetes and other metabolic conditions, respiratory illnesses, obesity, renal disease, cerebrovascular disease, and cancer.[6] Sixty percent of premature deaths in persons with schizophrenia are due to medical conditions such as cancer, heart disease, chronic obstructive pulmonary disease (COPD), and dementia.[7,8] These illnesses can be related to lifestyle factors such as tobacco use and obesity, so, in these instances, they can be viewed as preventable. Additionally, an estimated 26% of homeless adults staying in shelters live with serious mental illness.[9]

This chapter examines what is known about palliative care and persons living with mental illness, especially those with SPMI. Special issues related to communication and treatment are presented, as are strategies for care for this population. Ethical issues, including capacity and competence for decision-making as it relates to those with SPMI and end-of-life (EOL) care, are also discussed. Collaboration and consultation between providers is essential in providing palliative care for those with SPMI.

Research Related to SPMI and Palliative Care

Although the call for additional research has begun to ring a bit louder, little research has been conducted in palliative care of people with SPMI.[10] Much of the existing research has focused on identifying the increase in morbidity and mortality in this population and understanding what factors contribute to the increase. Those who have SPMI have been underserved in terms of healthcare in general and specifically palliative care.[11] Barriers to both care and research have been cited as (1) capacity of patients to make EOL decisions, (2) provider concerns that EOL discussions would be upsetting or trigger behavioral outbursts, and (3) lack of provider training and comfort in conducting difficult conversations required to assure quality EOL care.

Barriers to Care for Patients with SPMI

There are several barriers to consistent medical care for those with a mental illness; these barriers exist in primary care settings and apply to palliative care settings as well. Lack of preventive care or an ongoing relationship with a medical provider is a key issue for people with mental illness. People with SPMI often seek care later in the course of the disease, resulting in costly services and complex care needs. The inadequate support systems that are common among those with SPMI affect their ability to access medical care and navigate complex health systems. Adherence is a major problem in the treatment of people with SPMI, and adherence to medical regimens for this population is compounded by mental health and substance use issues, homelessness, or lack of transportation to get to medical providers. Lack of financial resources may complicate the patient's ability to receive timely care or treatment.[12]

Symptoms of SPMI can have profound effects on communication, which can result in problems with developing the therapeutic relationship.[13] In addition, symptoms of SPMI can have an impact on reporting of problematic symptoms or the effect of treatment on the symptoms. Trachsel et al.[14] found that a palliative approach to treating symptoms of schizophrenia may improve symptom response and decrease the risk of over- or undertreatment, thus improving outcomes for persons living with schizophrenia. Finally, stigma affects communication about all aspects of care of the medical illness, including assessment, explanation of treatment options, adherence, and the development of a trusting relationship with the patient.[13]

Severe and Persistent Mental Illnesses

SPMI includes disorders such as schizophrenia spectrum and other psychotic disorders, bipolar and related disorders, major depressive disorder, and personality disorders. Depression is described in detail in Chapter 22, but a brief discussion of schizophrenia spectrum and other psychotic disorders, bipolar and related disorders, and personality disorders will be presented here. A major feature of SPMI that can influence how these patients interact with the world around them is if psychotic symptoms are present, such as delusions and hallucinations. Psychotic symptoms, however, are not only associated with SPMI and can be seen in some patients with substance use disorders, anxiety disorders, and cognitive disorders such as dementia.[15] Treatment issues and special concerns in communication for persons with SPMI will be discussed as they relate to palliative care. The burden of SPMI is very high, so appropriate disease management will improve access to care and may reduce cost.[12]

Schizophrenia Spectrum and Other Psychotic Disorders

Schizophrenia spectrum and other psychotic disorders (schizophrenia, schizophreniform disorder, schizoaffective disorder, delusional disorder, brief psychotic disorder, and shared psychotic disorder or *folie à deux*) are characterized by delusions, hallucinations, disorganized speech and behavior, abnormal motor behavior (including catatonia), anhedonia, amotivation, blunted affect, and reduced speech.[3] Schizophrenia affects approximately 1% of the US population. However, it accounts for 40% of mental health facility beds and 9% of all hospital beds. It is a devastating illness to those who are affected—both the patient and the family of the patient. The symptoms of schizophrenia include what are categorized as positive symptoms (exaggerated or distorted function) and negative symptoms (diminution or loss of normal function). The positive symptoms include delusions, hallucinations, and disorganized and bizarre behavior and speech, as well as deterioration of social behavior. The negative symptoms include flattened affect, decreased range and intensity of expression, anhedonia, restricted thought and speech, amotivation, apathy, and difficulty in mental focus and ability to sustain attention. Other psychotic disorders share some or all of the same symptoms and differ by degree and the occurrence of additional characteristics.[3]

The symptoms associated with schizophrenia spectrum and other psychotic disorders may also be due to medications, substances, withdrawal from substances, and delirium due to other medical conditions. Such etiologies for the presenting symptoms must always be ruled out before assuming that there is a schizophrenia spectrum disorder or other psychotic disorder present. At the end of life, people with SPMI may appear to have a worsening of their condition when the issue may really involve an acute mental status change due to delirium in addition to their underlying illness.[3,15]

Some of the more limiting symptoms of schizophrenia spectrum and other psychotic disorders that are of particular concern in palliative care settings are the ability to participate in decision-making, perceptual difficulties that can affect sensory integration and concrete thought processes, and difficulty in attention and concentration. The effect of perceptual difficulties has been demonstrated in research related to pain sensation in people with schizophrenia. Patients with schizophrenia may have reduced sensitivity to pain, and this could lead to delays in care or treatment.[16]

Treatment of Schizophrenia Spectrum and Other Psychotic Disorders

Treatment of schizophrenia spectrum and other psychotic disorders is based on symptom management.[15] As in palliative care, there is no curative treatment for SPMI and all treatment can be considered palliative in nature. A diagnosis of an SPMI in the face of a serious or life-threatening illness indicates a referral to a palliative care program either in the hospital or in the community. Pharmacological and nonpharmacological interventions are both used to treat schizophrenia spectrum and other psychotic disorders. But nonpharmacological interventions may not be effective unless interfering hallucinations or delusions are brought under some degree of control first. The patient may then be able to participate in nonpharmacological interventions.

Pharmacological Treatment

Table 40.1 lists the first-generation antipsychotics, also known as conventional or typical antipsychotics.[17] These medications, developed in the 1950s and 1960s, are very effective in treating positive symptoms, and some—but not all—of these medications have an effect on negative symptoms. The side-effect profiles of these medications, including extrapyramidal symptoms (EPS), tardive dyskinesia (TD), and anticholinergic effects, have a profound negative effect on quality of life (QOL) and medication adherence.[17] Because the schizophrenia spectrum and other psychotic disorders are characterized by disordered thinking, patients who begin to feel better with treatment may still make bad choices, often leading them to discontinue their medication.

In the 1980s, development of the second-generation or atypical antipsychotics began (Table 40.1).[17] These medications reduced both the positive and negative symptoms associated with schizophrenia spectrum and other psychotic disorders, improved cognition, and were useful in the treatment of patients whose illness was refractory to the first-generation antipsychotics. The side-effect

Table 40.1 Medications used to treat schizophrenia and other psychotic disorders: generic and brand names

First generation, conventional, or typical antipsychotics	Second generation or atypical antipsychotics
Chlorpromazine (Thorazine)	Aripiprazole (Abilify)
Fluphenazine (Prolixin)	Asenapine Maleate (Saphris)
Haloperidol (Haldol)	Clozapine (Clozaril)
Loxapine (Loxitane)	Iloperidone (Fanapt)
Molindone (Moban)	Lurasidone (Latuda)
Perphenazine (Trilafon)	Olanzapine (Zyprexa)
Pimozide (Orap)	Paliperidone (Invega)
Prochlorperazine (Compazine)	Quetiapine (Seroquel)
Thioridazine (Mellaril)	Risperidone (Risperdal)
Thiothixene (Navane)	Ziprasidone (Geodon)
Trifluoperazine (Stelazine)	Olanzapine/Fluoxetine* (Symbyax)

* combination atypical antipsychotic and SSRI

Source: From Reference 17.

profile of the second-generation drugs showed lower rates of EPS and TD and fewer anticholinergic effects. The emergence of metabolic syndrome as a side effect of the second-generation antipsychotics—including pronounced weight gain, diabetes, hyperlipidemia, and hypercholesterolemia—has resulted in the need for close monitoring of their use in treating schizophrenia spectrum and other psychotic disorders.[17] These medications result in cardiovascular problems and compound the existing higher prevalence of cardiovascular problems in people being treated for schizophrenia spectrum and other psychotic disorders.[17]

Pharmacological treatment of psychotic symptoms in conjunction with palliative care treatment should be closely monitored by consultation with psychiatric providers. Hospital protocols for certain physiological presentations immediately trigger discontinuation of oral medications. In the case of a person with a schizophrenia or other psychotic disorder, this could initiate decompensation and a relapse. The palliative care nurse knows to advocate for alternate routes for antipsychotic administration in these cases.

Any change in mental status should be immediately evaluated. Screening for the presence of delirium, both hyperactive and hypoactive delirium, which can occur frequently at the end of life, should occur with any change in mental status. The nurse should not presume that the psychiatric illness is the cause of a mental status change until a physical cause is ruled out.[15]

Several of the typical and atypical antipsychotic medications share common metabolic pathways with opioid analgesics. Inhibition or potentiation of the antipsychotic or the opioid medication is possible; therefore, close monitoring is essential.[17] When caring for persons being treated with antipsychotics in palliative care settings, the nurse must be aware of the cardiac effects of adding haloperidol to treat nausea and vomiting, which is common in palliative care, such as QTc interval prolongation.[17]

Nonpharmacological Treatments

Nonpharmacological interventions for the treatment of schizophrenia spectrum and other psychotic disorders include psychotherapeutic strategies such as supportive psychotherapy, cognitive-behavioral therapy (CBT), group therapy, skills training, and integrative therapies such as mindfulness training and relaxation.[18] Collaborative care with psychiatric providers can include additional supportive therapy to assist patients facing a terminal illness. People with SPMI face the same EOL concerns as patients without mental illness, such as dealing with pain and suffering, fear of what lies ahead, fear of becoming a burden, spiritual concerns, financial concerns, and difficulty saying goodbye.[19] People with schizophrenia or other psychotic disorders may need additional support and extra time to process medical information. This extra support is best provided by professionals who already have a relationship with the patient. The patient's psychiatric providers, therefore, should be included in discussions of treatment options in the palliative care setting.[20]

Communication and Schizophrenia Spectrum and Other Psychotic Disorders

Communication issues and special strategies are involved when providing palliative care to those with schizophrenia spectrum and other psychotic disorders. The role of stigma affects all aspects of care and communication. Patients may conceal or not report pain and other symptoms because of fear of the meaning of the symptom, self-blame, guilt, anger, or denial. As mentioned previously, mental status changes should be evaluated for a medical cause of delirium before assuming that altered perceptions or hallucinations are the result of mental disorder.

If the patient is actively delusional or hallucinating, then a safety assessment should be completed and arrangements made to keep the patient safe from harm. The content of the hallucinations or delusions can be very important. Any thoughts or hallucinations that patients express concerning the need to die or to hurt themselves or others, or the presence of command hallucinations telling them they need to die or to hurt themselves or others require immediate psychiatric consultation. Patient safety interventions, such as clearing the environment of any potentially harmful items, evaluation by emergency services (for outpatient settings), or the use of sitters or frequent observation (for inpatient settings) should be instituted until the psychiatric assessment can occur.

Maintaining a calm presence and use of a quiet tone of voice and nonthreatening demeanor and stance are important strategies when dealing with all patients who are actively psychotic. Reducing environmental stimuli, such as turning off a radio or television, will decrease distractions and help the patient focus on the immediate medical care. Because the ability to concentrate or pay attention may be affected by the mental illness, detailed explanations may be needed, with additional time allowed for the patient to process the information. Conversations focused on understanding what the patient has processed about the information may need to take place over lengthened periods of time. Patients may also tend to focus on concrete parts of the information, and it can be helpful to provide alternative ways to view the situation if a patient appears to be stuck or focused on one particular aspect of the issue. Occasionally, people with schizophrenia spectrum and other psychotic disorders may become more focused and less psychotic in the face of a life-threatening illness.

Patients with SPMI who are actively hallucinating or delusional, as well as those who may be delirious and experiencing altered perceptions, should receive explanations of all physical care to be delivered. Before touching the patient, it is important to let him or her know what is to be done because the patient might misinterpret the touch and react as if he or she is being assaulted. Patients with SPMI may have a different sense of private space and may also react to violations of personal space.

Case Study: A Patient Living with Schizophrenia

JD is a 59-year-old male patient who was diagnosed with schizophrenia 35 years ago just after leaving college, where he studied engineering. He experienced command hallucinations telling him to not take his medication and to not answer the door because "they were going to hurt him." His immigrant parents did not understand what was happening to their only child and grew weary of trying to help. JD reports that they stopped calling and visiting 20 years ago.

Early in his illness, he was stabilized on clozapine, but, over time, he developed leukopenia and severe extrapyramidal symptoms including cogwheeling, akathisia, and tardive dyskinesia that became refractory to pharmacologic treatment. The trajectory of his schizophrenia included periods of recovery interrupted by him not taking his medicine and experiencing a relapse of his symptoms. He was switched to an oral formulation of risperidone, which helped reduce the frequency of relapses, but, at times, he was not physically present to receive his regular injection. Over the course of his illness, he has alternated between being homeless, living in a group home, and living in subsidized housing when he was not hospitalized to restabilize.

JD was diagnosed several years ago with COPD related to his chronic smoking habit. He continued to smoke despite the effect on his health, and, at this diagnosis, he was linked with a community palliative care program for symptom management. Recently, he was diagnosed with stage IV lung cancer and moved to a group home for persons with severe and persistent mental illness. The interdisciplinary palliative care team met with JD and with the mental health care team to determine JD's goals of care. He reported that although he was just diagnosed with lung cancer and was offered chemotherapy, he said, "I have been taking strong, awful medications all my life. I don't want to put all that extra poison in my body." The palliative care team looked to the mental health staff for guidance, who determined that although JD had cognitive impairments due to his schizophrenia, he could make decisions for his own healthcare, even if his track record was replete with poor choices. The mental health staff at the group home were concerned that they might not be able to provide the care JD needed as the course of his life ended, but the registered nurses on his mental health treatment team advocated for him and asserted that they would support his hospice needs in collaboration with the hospice team.

This case illustrates several issues of importance:

- The capacity and the ability of patients to make their own decisions should be assumed despite diagnosis, unless there is a clear reason to suspect impaired capacity.
- Regular medical care of patients with SPMI is paramount, particularly due to side effects of pharmacotherapy and the tendency for self-medication with tobacco, alcohol, and other substances.
- Chronic severe mental illness can deplete family coping resources.
- The definition of "family" must be expanded. Nursing staff are the ones with most regular contact and can advocate for patient's wishes regarding care.
- The collaborative approach is essential, crossing palliative care and psychiatric and mental health care to assure QOL in the face of a terminal illness for persons living with SPMI.

Bipolar and Related Disorders

Bipolar and related disorders have a fluctuating course that often results in recurrent episodes of inflated mood (hypomania or mania) with or without depressed mood (depression). They include bipolar I disorder, bipolar II disorder, and cyclothymia.[3] All persons have fluctuating moods. But with bipolar and related disorders, the normal controls are out of order, and mood fluctuations swing to beyond-normal extremes. People with bipolar and related disorders frequently discontinue their medication because of unwanted side effects and because the feelings associated with hypomania may result in increased productivity, creativity, and pleasure. Bipolar and related disorders are often comorbid with other psychiatric disorders, particularly with alcohol or substance use disorders. People with bipolar and related disorders have more co-occurring medical conditions—especially cardiovascular disease and other problems related to metabolic syndrome—than those with other chronic mental illnesses.[21] As with schizophrenia spectrum disorders, episodic exacerbations of mood often affect a person's ability to function within the context of his or her role in the family and at school or on the job. The use of atypical antipsychotic medications as mood stabilizers for those with bipolar and related disorders has increased the risk of diabetes and subsequent cardiovascular disease among people with this diagnosis.[17]

Symptoms of hypomania or mania include inflated self-esteem, grandiosity, decreased need for sleep, pressured speech, flight of ideas, increase in activities, and excessive involvement in pleasurable activities that have a high potential for negative consequences.[3] Severe mania can present more with symptoms of agitation than euphoria and often includes episodes of delusions, paranoia, and hallucinations, as well. Symptoms of depression can include sleep changes (insomnia or hypersomnia); anhedonia or loss of interest in things that were formerly of interest; feelings of guilt, hopelessness, or helplessness; decreases in energy; difficulty concentrating; changes in appetite (up or down); and psychomotor changes (agitation or slowing). Suicidal feelings, ideation, or attempts can also accompany depression, so safety is of utmost importance.[3]

Treatment of Bipolar and Related Disorders

Assessment of persons with bipolar and related disorders is the first step of the nursing process. See Chapter 4 for assessment of the patient and family. Accurate assessment is of particular concern in treating disordered mood. Inaccurate assessment of depressive symptoms as a part of differentiating major depression and bipolar depression may result in initiation of antidepressant medication that could precipitate a manic episode in someone with a bipolar disorder. Additionally, people with bipolar disorders are at a higher risk for suicidal ideation than those with any other psychiatric disorder.[15]

Pharmacological Treatment

Treatment of bipolar and related disorders includes first treating any delusions or hallucinations with an atypical antipsychotic and then adding mood-stabilizing medications such as lithium

Table 40.2 Medications to treat bipolar and related disorders: generic and brand names [17]

Mood stabilizers	Calcium channel blockers
Lithium (Eskalith, Lithobid)	Verapamil (Calan)
Lithium citrate	Nifedipine (Procardia)
	Nimodipine (Nimotop)
Anticonvulsants	Benzodiazepines
Valproic acid (Depakene, Depakote)	Alprazolam (Xanax)
Lamotrigine (Lamictal)	Chlordiazepoxide (Librium)
Carbamazepine (Tegretol)	Clonazepam (Klonopin)
Gabapentin (Neurontin)	Diazepam (Valium)
Oxcarbazepine (Trileptal)	Lorazepam (Ativan)
Pregabalin (Lyrica)	Oxazepam (Serax)
Topiramate (Topamax)	Prazepam (Centrax)
Tiagabine (Gabatril)	

Source: From Reference 17.

and other drugs (Table 40.2).[17] Benzodiazepines are often used to supplement the use of antipsychotics and mood stabilizers, and antidepressants can be used in the treatment of depressive symptoms along with the mood stabilizers.[15,17]

When patients are in a manic state or a severe depression, they may lack decision-making capacity but are then often capable of making decisions when they become stable. A psychiatric provider should be a part of the palliative care team and provide close follow-up. Any medications used in treatment of the underlying medical illness should be reviewed for their potential to induce a manic episode, such as dopaminergic anti-Parkinson's medications, sympathomimetics, corticosteroids and anabolic steroids, thyroxine, and amphetamines. As with schizophrenia spectrum disorders, there are many psychotherapeutic interventions that are used in the treatment of people with bipolar and related disorders. Patients frequently need to be stabilized with medications first, however, before these treatments can be used effectively.

Nonpharmacological Treatment

A variety of psychotherapies have been used with bipolar and related disorders; most often therapies are used in conjunction with psychopharmacological interventions once active mania has stabilized. Interpersonal therapy and CBT are two of the most widely used therapies with these disorders. Patient and family education is essential, as is social and coping skills training.[15] The application of integrative therapies in treating bipolar and related disorders, such as mindfulness training and the use of SAMe and omega-3 fatty acids, has been recorded, but their helpfulness has not been demonstrated.[22]

Communication Issues and Bipolar and Related Disorders

Communicating with someone during a manic episode can be difficult because patients may be emotionally labile and very talkative (with pressured speech), may not be able to stop and listen or concentrate, and often reject help.[3] Patients can be quite charming and even entertaining during some early stages of a manic episode. Staff members need to see these presentations as a part of the illness and not join in grandiose discussions or plans. Patients may need to be gently redirected so that they do not go off on tangents unrelated to the medical issue at hand. They may also need firm but caring limits set on behaviors that might affect others' care, such as wandering into other patients' rooms, becoming inappropriately involved in others' care, and intruding on staff conversations with other patients. Assisting patients in calming behaviors such as sitting quietly with the patient or closing the door to the room to decrease external stimuli are strategies that may be helpful. Inclusion of the psychiatric provider in the team will allow for communication of information about the best approach to take with an individual with a bipolar disorder.[13]

Often, one of the first symptoms of a manic episode is the decreased need for sleep.[15] Early reporting of changes in sleep habits is important because it is easier to help someone regain stability early during a manic episode. If the patient is beginning to exhibit signs of mania or psychosis, then assessment of safety issues and the potential for suicide must be considered. The importance of early intervention in escalating symptoms and good interteam communication cannot be emphasized enough when caring for someone with a bipolar or related disorder.

Case Study: A Person Living with Bipolar I Disorder

CA is a 40-year-old single African American female patient with a long-term diagnosis of bipolar I disorder. The course of her illness has been very difficult, punctuated by multiple hospitalizations after attempting suicide. As a patient of a community mental health service, she is seen by a psychiatric and mental health nurse practitioner (PMHNP) in the clinic, has an outreach registered nurse who follows up with her at home, and has a case manager who assists with getting to appointments and linking to community support services, including food banks, housing, and Medicaid. She takes lithium carbonate and valproic acid for mood stabilization. CA lives in an apartment that is paid for by her younger sister and who has been able to secure legal guardianship over CA's person and finances through the courts.

CA was obese, had metabolic syndrome, and had congestive heart failure. Her sister did not want to think about her sister being terminally ill, so she encouraged her to "get healthy, eat better, and exercise." Despite her frequent suicidal thoughts and previous attempts, CA said that she wanted to live and was determined to enjoy the time she had left with her sister and her sister's children. "I don't want to change a thing and I want to enjoy my life while I can." CA's sister took issue with this, but the palliative care team agreed to continue to work with CA and her symptoms, trying to keep her out of the hospital; subsequently CA's sister completed the paperwork to enroll her in hospice.

This case highlights several factors that are important in the palliative care of patients with mental illness:

- Some patients with suicidal histories may put suicidal tendencies aside in the face of a terminal illness and fight to live, in a different way than their history would indicate, as long as their QOL is satisfactory.
- Families may be in a crisis when encountering an unexpected medical illness in the context of a severe and persistent mental illness.

Personality Disorders and Palliative Care

People with personality disorders (PDs) can present major challenges for palliative care providers, in part because of the maladaptive coping strategies used in light of the associated personality traits and in part because of the stigma associated with PDs.[15] Personality traits are enduring patterns of perceiving, relating to, and thinking about the world and how one relates to it.[3] The enduring patterns of response and behavior deviate from social norms and present in the areas of:

- *Cognition*: Ways of perceiving self, others, events
- *Affectivity*: Range, intensity, lability, appropriateness
- *Interpersonal functioning*
- *Impulse control*

There is a lack of flexibility and also maladaptive behavior that can cause impairment in function and distress for the person and those with whom the person interacts.[3]

All humans have vulnerabilities that are accentuated when the person is under stress. Approaching personality traits as vulnerabilities that are accentuated by stress and that therefore result in the use of predictable coping mechanisms can be a useful way to change stigmatized attitudes toward people with PDs. It is important to identify traits or vulnerabilities and move beyond labels so that treatment can be geared to preparing for the expected response and minimizing maladaptive coping mechanisms and replacing them with more functional coping mechanisms.

In the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-5), personality disorders are grouped into three clusters based on some descriptive similarities.[3] Cluster A PDs include paranoid PD, schizoid PD, and schizotypal PD. People with Cluster A disorders often appear odd, eccentric, or paranoid. People with paranoid PD have a pervasive distrust and suspiciousness of others. The person will be reluctant to trust or confide in anyone and may suspect that others are trying to cause him or her harm.[3] The person with schizoid PD has a pervasive pattern of detachment from relationships, even with family. This person prefers solitary activities, lacks close relationships, and may be emotionally detached or have a flat affect.[3] People with schizotypal PD are uncomfortable with close relationships and have cognitive distortions, including ideas of reference, odd beliefs or magical thinking, unusual perceptions, odd thinking and speech, inappropriate affect, and social anxiety.[3]

Cluster B PDs include antisocial PD, borderline PD (BPD), histrionic PD, and narcissistic PD. People with this group of PDs often appear dramatic, emotional, or erratic, and it is this cluster that often presents the biggest challenge to healthcare providers. The person with antisocial PD has a pervasive disregard for and often violates the rights of others. They fail to conform to most social norms and can be impulsive, irritable, and aggressive at times.[3] People with BPD have a lifelong pattern of instability in interpersonal relationships and self-image and either idealize or devalue others, or fluctuate between these two views of the same person. People with BPD are impulsive in ways that are damaging to themselves and frequently have recurrent suicidal behavior. They have a chronic feeling of emptiness and therefore constantly seek attention and contact with others to fill themselves.[3] People with histrionic PD have a pattern of excessive emotionality and attention-seeking and can be inappropriately provocative or sexually seductive. People with these traits are easily influenced by others and often consider relationships to be more intimate than they actually are.[3] People with narcissistic PD need admiration, have a lack empathy for others, and have a sense of entitlement.[3]

Cluster C PDs include avoidant PD, dependent PD, and obsessive-compulsive PD. These disorders share anxiety and fear as their major characteristics. The person with avoidant PD is hypersensitive to negative evaluation, has feelings of inadequacy, and is severely restrained in relationships. This person is reluctant to take personal risks or engage in new activities.[3] Someone with dependent PD has an excessive need to be taken care of that exhibits itself by submissive and clinging behavior and fear of separation. People with this PD have difficulty making decisions and need a lot of advice and reassurance from others. They have difficulty expressing disagreement with others because of fear of loss of support.[3] Obsessive-compulsive PD is evidenced by a preoccupation with orderliness, perfectionism, and control. The person with obsessive-compulsive PD shows perfectionism that interferes with completion of tasks, is inflexible and overly conscientious, may be unable to throw out useless objects, and is miserly toward spending on self and others. This person may be quite rigid and stubborn in thought and behavior.[3]

Treatment of Personality Disorders

By description, PDs are enduring patterns and, therefore, are not likely to change rapidly. Current evidence does suggest that people with PDs can be treated, but realistic goals must be established for treatment. Symptom management and specific therapies such as CBT and dialectical behavioral therapy (DBT) have demonstrated effectiveness with specific PDs.[18] A relationship with a psychiatric provider is a primary tool in the treatment of people with PDs. There is no medication with a US Food and Drug Administration (FDA) indication for treatment for personality disorders. Comorbid psychiatric conditions are common with PD, so symptom management of anxiety, depression, and other psychiatric symptoms is important to improve QOL.[18]

Communication Issues and Personality Disorders

Some general principles related to communication with patients with PDs include:

- Provide clear information verbally and in writing, with repeated discussions about the information to help with distortions and misinterpretation that are common in people with PDs.
- A calm and nonjudgmental approach is also the cornerstone of good communication in the process of developing a therapeutic relationship with patients.
- All discussion of suicidal ideation should be taken very seriously and a thorough psychiatric assessment should be performed, even when repeated threats of suicide occur.
- The therapeutic alliance may take a long time to develop, but nonetheless the development of this alliance is a goal for treatment.
- The techniques of CBT are helpful for people with PD to examine maladaptive ways of viewing their environment.
- Supportive therapy is useful in helping people with PD adjust to the issues that arise in palliative and EOL care.

Obstacles to therapeutic communication that occur with people with PDs include issues such as resistance, transference, countertransference, and boundary violations.[15]

- *Resistance* is often unconscious and is usually employed by patients to avoid anxiety.
- *Transference* is an emotional reaction of the patient toward the healthcare provider in which the patient unconsciously transfers feelings or attitudes from someone in their personal life onto the healthcare provider.
- *Countertransference* is the emotional reaction of the healthcare provider toward the patient in which the healthcare provider unconsciously transfers feelings or attitudes from someone in their personal life onto the patient. When the provider feels a gut response toward the patient, countertransference is occurring and one's feelings must be checked in support of the therapeutic relationship.
- *Boundary violations* occur when one party—the patient or the healthcare provider—breaks down the professional curtain of the therapeutic relationship and enters into a more social relationship. This confounds roles and causes confusion, which is not therapeutic. The healthcare provider is charged with maintaining professional boundaries and to cueing the patient when he or she has violated boundaries with them or with others.

Communication issues with patients diagnosed with Cluster A disorders arise from distrust, suspicion, and withdrawal from personal interactions. Thus, therapeutic communication focuses on establishing and maintaining the therapeutic relationship. Presenting a nonthreatening approach and allowing the patient to engage with the provider at his or her own speed is very important. The intensity of a one-to-one conversation may be difficult for those with Cluster A PDs. Focusing conversation on an external issue or task, therefore, may be a helpful way to lessen the intensity.

Communication issues with people diagnosed with Cluster B disorders are often the most problematic for healthcare providers. People with these disorders tend to have an increased risk of suicide, violence toward others, and self-mutilating behaviors as well as chronic low self-esteem, ineffective coping, and impaired social interactions. Volatile changes in emotion as well as splitting behaviors—attempts to cause a rift between others so that the patient becomes the focus of the attention of those they have broken apart, such as the nursing staff—are characteristic of BPD. Development of a consistent approach will minimize the patient's ability to split staff and minimize the heightened feelings that can arise in caring for this population.

Providers should be alert for their own countertransference reactions toward patients with PD, which happens not infrequently. Patients with PD can evoke strong reactions from staff that may interfere with delivery of quality care. Staff support in working through these reactions so that care is not affected can be provided through consultative relationships with psychiatric providers. Many advanced practice psychiatric registered nurses (PMH-APRNs) have experience with staff support groups to handle such issues.

Communication issues with people diagnosed with Cluster C disorders also focus on the development of a therapeutic relationship geared toward assisting patients in identifying their fears and anxiety as it relates to palliative care treatment. Helping people identify their anxiety, decrease their maladaptive responses to anxiety, and increase their supportive relationships with others are essential issues in dealing with people with Cluster C diagnoses.

Case Study: A Person Living with Borderline Personality Disorder

LG is a 44-year-old single Caucasian female patient diagnosed with breast cancer with metastases to the brain and spine that has progressed to stage IV. She lives at home with her three late-teen daughters, their combined four children, and two of the four baby-daddies. She is enrolled in her third hospice program in the past year, having "fired" the previous two hospice programs because "they weren't taking care of me." One of the nurses from the first hospice program, BB RN, resigned because of this "difficult patient." When BB RN found that LG was later enrolled in the hospice program at which she was newly employed, she told everyone on the staff about her previous experiences with LG.

When the nurses came to LG's home, LG frequently was not home. Her daughters did not know where she was or when she would be back home, thus making scheduling visits difficult. When she was there, she would talk about the other nurses who were seeing her and tell today's nurse that he or she "was my favorite." When the nurses checked on her medication packets, medicines were missing and not recorded in the log. LG would call the triage nurse during the night "just to talk" and then complain profusely to the nurse manager that the triage nurse was not taking care of her pain. She demanded a direct phone number to call the nurse manager at any time day or night so she would have her needs met. LG would also call 911 and demand to be taken to the hospital for inpatient hospice because her symptoms were "out of control."

The team of hospice nurses were exasperated during team meetings and complained when they saw LG on their census. BB RN would incite uneasiness by regaling the team with stories from her previous place of employment. The nurse manager reprimanded BB RN for violating privacy policy in regard to this patient and wrote her up. He then asked the team to please try to be more patient with LG and to make sure they talked about things the patient was telling each one to minimize internal discontent.

On one visit, the RN noticed that LG was not her usual self. She was lying in bed and moaning, saying that she was in terrible pain and was not able to catch her breath. She had not slept at all the night before and said her pain was "10 or more" out of 10. The RN, following protocol, gave her a dose of her pain medicine, which improved her pain to "an 8" and called the triage nurse to facilitate transport to the hospital. Before transport arrived, LG said to the nurse, "I know I'm dying! I don't want to die! I'm too young to die! Please don't let me die!"

LG was admitted to the inpatient unit and the interdisciplinary team invited a psychiatric service to participate in care planning. The hospice nurse manager also established a round-table discussion for the outpatient RNs to process their experiences with LG and to assure that all patients, regardless of their diagnosis, were treated with dignity and respect.

This case highlights several factors in the care of people with personality disorders:

- The labeling of those with personality disorders as "difficult patients" can result in stigma and less than optimal care unless someone is able to be a role model in terms of providing the best care possible for the patient.
- Each encounter with patients with PD may be quite different.

- Identifying maladaptive coping mechanisms may help staff understand patient behavior and assist them in developing a nonjudgmental approach to the patient.
- Allowing time for staff to vent and examine their reactions to and feelings about dealing with patients who upset them can help nurses improve care to patients with PD.

Ethical Issues

Several ethical issues related to the care of people with mental illness, especially SPMI, in palliative care require consideration over and above the consideration given to people without mental illness. Care of vulnerable populations such as those with mental illness carries a greater obligation for nurses to provide advocacy and protection from violation of the patient's autonomy and right to make decisions about care.

Right to Refuse Medication

In the 1970s, psychiatric patients filed lawsuits related to their rights to refuse medication. Legal decisions in Massachusetts and New York, the states where the most prominent cases were filed, resulted in different approaches to the problem. The 1983 decision of *Rogers v. Commissioner of Department of Mental Health* (390 Mass 489) (1983) decreed that if a psychiatric patient refuses to take an antipsychotic and the patient is determined to be incompetent, a guardian must be appointed to implement the use of the psychiatric medication in question as determined by the judge. The concept of substituted judgment—that is, what the person would consent to if he or she were competent—is how the judge evaluated the question of whether to give the guardian the right to overrule the patient's right to refuse medication.[23] Other states have panels, independent consultants, or psychiatric care providers to make the decision about the right to refuse medication. The nurse must understand what his or her state nurse practice act says about the right of patients to refuse medication to provide safe, effective, and appropriate care to their patients with mental illness.

Advance Directives

The ability of a patient to document decisions about psychiatric care in the future is available, but not widely used. The palliative care nurse will know to ask patients with psychiatric diagnoses for these documents. The National Resource Center for Psychiatric Advance Directives (http://www.nrc-pad.org/state-by-state) has a directory of resources for professionals in each state with a psychiatric advance directive statute (currently, these are Arizona, Hawaii, Idaho, Illinois, Kentucky, Louisiana, Maine, Maryland, Michigan, Minnesota, Montana, New Mexico, North Carolina, Ohio, Oklahoma, Oregon, Pennsylvania, South Dakota, Tennessee, Texas, Utah, and Washington). Providing a patient with the opportunity to discuss his or her wishes in advance has assisted with decreasing the need to have a legal competency hearing to determine a course of treatment during a crisis. Including a discussion of the patient's wishes for EOL care, however, needs additional research. Current evidence has indicated a low rate of advance directives for either psychiatric care or medical care in patients with SPMI.[24]

Capacity and Competence

The right of the patient to make decisions about goals of care and care planning is a cornerstone of palliative care. Controversy can occur when a person loses the ability to participate in informed decision-making about their healthcare or when a person refuses life-sustaining treatments.[25] A general rule is that all persons with the ability to make their own decisions have the right to make their own decisions, even when decisions conflict with what a majority would decide under similar circumstances. When the patient is a person who has a psychiatric disorder that affects cognition and judgment, the ability to make decisions may be compromised by their impairment. However, having a diagnosis of a mental illness, even one with cognitive impairment, does not automatically mean that a person does not have the ability to make his or her own decisions. When healthcare decisions must be made with or without advance directives, and the ability of the patient to make his or her own decisions is in question, then a psychiatric evaluation must be requested to determine the patient's ability to make healthcare decisions. If the answer confirms that the patient does not have capacity and advance directives had already been prepared, then these advance directives are followed.

The word "capacity" means the ability to understand the problem and make decisions. A psychiatric provider makes a clinical assessment of the patient's ability to function in certain areas. "Competence," however, is a legal term and is decided by a court of law based on the capacity assessment of a psychiatric provider and other data points. Competence is usually confined to a specific area or task, such as the ability to make a will, the ability to testify in court, the right to make the decision to leave the hospital, or the right to refuse treatment. In general, four criteria are used to determine capacity to consent to treatment:[26]

- Does the patient express a preference?
- Does the patient understand the illness, the prognosis with and without treatment, and the risks and benefits of the treatment (also known as factual understanding)?
- Does the patient appreciate the significance of the facts?
- Can the patient use the information in a rational way to reach a decision in a logical manner (also known as rationality of the thought processes)?

When all four questions are answered in the affirmative, the patient has capacity to consent to treatment.

Intense pain, depression, delirium, dementia, and psychosis are the most common causes of incompetence. The existence of one of these conditions, however, does not necessarily mean that a person is incompetent. Careful assessment of each individual is necessary to determine capacity and competence. A patient is not deemed competent or incompetent until a court of law rules. Once a determination of incompetence is made, a guardian is typically assigned to make decisions on behalf of the patient.[24]

Aggression and SPMI

Patients enter healthcare systems in great distress, and palliative care settings are no exception. When the patient has an SPMI, the distress may be even greater than in the general population because people with SPMI may have inadequate coping resources and are in a crisis state when dealing with a life-threatening illness. Most often, people become aggressive when they feel threatened in some way. The aggressive behavior may be the result of perceptual problems, such as hallucinations or delusions, and the aggressive behavior often masks a lack of confidence in self. Aggressive behavior may be a way to enhance self-esteem by overpowering others.[15]

There are some important predictors of aggressive behavior, including impulsivity, hostility, family history of violent or abusive behavior, substance use, and irritability.[15] Prevention of aggressive behavior focuses on early recognition of escalating behaviors, such as pacing, nonverbal expressions, yelling, or an angry tone of voice. Allowing the person a chance to talk may defuse the situation. The use of nonthreatening body language is imperative, as is communicating with a calm but firm voice while conveying respect for the patient and the patient's feelings. Allowing the patient some choice about the situation is often a way to help the patient gain some control.

Communication Issues and SPMI

One hallmark of both palliative care and psychiatric care is the importance of communication to establish and maintain a trusting, therapeutic relationship between the nurse and the patient. Traditionally, psychiatric providers are not comfortable with medically ill patients and medical providers are not comfortable with psychiatrically ill patients. Additionally, many people with mental illness are housed in nontraditional settings. Staff in any of these settings, including medical hospital units, palliative care units, or psychiatric units, as well as homeless shelters, prisons, and nursing homes, may be ill-equipped to deal with psychiatric problems and terminal illness. Education of all staff about mental illness and EOL care in these settings will result in better care for patients with SPMI.

Family Issues

For many people with SPMI, the ties with family members are strained, distant, or nonexistent. Some of this disconnection may be the result of years of strain, disappointment, financial burden, and fear caused by threatening behavior. Families of patients with SPMI may also have their own mental health issues and may use defensive strategies such as denial or anger in dealing with medical problems. Additionally, family members may have been dealing with chronic sorrow related to the mental health issues of the family member, may be overprotective, and may be psychologically fatigued due to years of care-taking responsibilities. Careful assessment of family functioning in these situations may be beyond the scope of the hospice and palliative care nurse and may require consultation with psychiatric providers.

When the patient is competent and there is discord in the family, conflict may arise if providers are restricted about the information they can give to the family due to the provisions in the Health Insurance Portability and Accountability Act of 1996 (HIPAA) or when the patient refuses to include family in healthcare discussions. A family member who has been the caregiver for the patient for years and is then shut out from information about the medical illness and treatment options may respond with anger and frustration. Family meetings may be of help in these situations; if there has been an involved psychiatric provider, this person should be included in the meetings. If there has been no psychiatric provider, then consultation with a psychiatric provider prior to a family meeting may be useful. Finding out which supportive services, if any, have helped the family in dealing with the mental health issues is vital. Groups such as the National Alliance on Mental Illness (NAMI, www.nami.org) have been a tremendous support to families with a member with a mental illness. NAMI also runs support groups for family members, and families may have established connections with these groups; if so, they should be encouraged to increase their participation in these groups. These NAMI groups may not be focused on EOL issues, but they are familiar with many of the ethical/legal aspects of caring for someone with a mental illness and may be more appropriate than a support group for families focused only on EOL issues. As with any patient and family, careful assessment will be key in developing the best treatment approach for the individual and their family.

Many people with SPMI are cared for by state governments, and long-term relationships with psychiatric providers or staff of mental health housing programs may have become a substitute for family. The inclusion of these staff into the palliative care team is essential to ensuring that the treatment will be properly performed and for providing the day-to-day intensive support that may be required for the patient. Like family, staff will also have their own particular needs for support because most psychiatric providers do not have EOL care experience or education. Fellow patients with SPMI make up the other component of family that needs to be considered in palliative care of people with SPMI. Occasionally, long-term relationships with other people with SPMI are the most significant relationships in the person's life. Special needs for support should be considered for this group of people as well. Although palliative care staff may not be involved in delivering this support, collaborative partnerships with psychiatric providers should be available to provide support for this group of people.

Conclusion

Palliative care providers often feel poorly prepared to deal with people with SPMI. Conversely, psychiatric providers feel poorly prepared to deal with medical care and palliative care, particularly at end of life. Efforts are being made to include more palliative care information in educational preparation programs, such as the American Nurses Association's End-of-Life Nursing Education Consortium (ELNEC; www.aacnnursing.org/ELNEC). Collaborative partnerships are key to enhancing the care given to people with SPMI who need palliative care services. Care delivery sites need to be examined for the optimal situation to provide both palliative care and treatment in an environment that also can provide optimal support and treatment by psychiatric providers. If the patient prefers a place to receive EOL care, all attempts possible can be made to address this preference. If the person considers a group home to be their home, and they desire to die at home, providing EOL care in that setting should be discussed just as it would be with a person wanting to die in a private home. Nurses have often been instrumental in making this kind of care possible in a situation that has not previously involved this level of care. As strong advocates for their patients, nurses have found a way to insert themselves into new arenas of care and have developed new collaborative partnerships for the ultimate benefit of their patients. For example, Chovan[27] has proposed a crosswalk of collaboration between psychiatric nursing and palliative care nursing that emphasizes the similarities and differences to assist nurses and nurse educators to prepare tomorrow's workforce. Collaboration between psychiatric providers and palliative care providers is an emerging area in which nurses can lead the way to ultimately provide new skills for each other and meaningful palliative care experiences for people living with SPMI and their families.

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CHAPTER 41

Palliative Care for People Living with HIV

Jacquelyn Slomka

Key Points

- Over more than three decades, HIV has evolved from a terminal illness to a manageable chronic illness.
- People living with HIV (PLWH), especially those who are developing additional chronic diseases as they age, can benefit from early palliative care.
- In assessing PLWH for palliative care services, clinicians should be aware of the association of HIV with mental health issues and substance use.
- Perceptions of stigma associated with HIV/AIDS and marginalized lifestyles may interfere with effective care of PLWH.
- PLWH may be wary of advance care planning discussions because of the historic association of palliative care, hospice, and death prior to the extraordinary advances in treatment for HIV.

Introduction

People living with human immunodeficiency virus (HIV) present unique challenges for the provision of palliative care due, in part, to the nature of HIV infection and its medical and social history. Since the virus was identified more than three decades ago, the world has witnessed a remarkable evolution of a (then) newly emerged disease condition and its eventual clinical control. At its onset, HIV was a mysterious infection, associated first with gay men and not amenable to treatment with traditional antibiotics.[1,2] Individuals who contracted HIV in this early period most often experienced progression to acquired immunodeficiency syndrome (AIDS), with inevitable death. The spread of HIV and its progression to AIDS created a pandemic affecting people of all ages.[1,2]

Scientists learned that HIV infection was caused by a type of virus called a “retrovirus” which attacked the body’s immune system, causing a deficiency of CD4 (T) cells that allowed opportunistic infections and certain cancers to occur.[1,2] AIDS is generally defined as severe progression of HIV infection or as the presence of a CD4 count of less than 250.[1,2] The virus is spread through certain body fluids; risk of transmission was higher with certain activities such as sexual behaviors and injection drug use.[2] Over time, little progress was made in producing a vaccine to prevent HIV. But advances in drug treatments were made, and the deadly epidemic was transformed into a manageable chronic disease. Still without an effective vaccine, prevention efforts in recent years have focused on the use of pharmacological agents for pre- and postexposure prophylaxis.[3] As further evidence of the evolution of this once-deadly infection into a controllable chronic condition, the Center for Disease Control and Prevention (CDC) reported that studies now show viral suppression (i.e., reducing the levels of HIV in the blood and body to a very low or undetectable level) is the best way for PLWH to maintain health and prevent HIV transmission.[3,4,5]

HIV may not evoke the fear that it once did in the past, but it still remains a significant public health threat. The CDC estimates that 1.1 million people in the United States are living with HIV and that 1 in 7 individuals are not aware they are infected.[6,7] Although the CDC estimated that the number of HIV diagnoses decreased by 5% between 2011 and 2015, a reported 39,782 individuals were newly diagnosed in 2016.[6] According to the CDC, the largest number of diagnoses were among gay and bisexual men (26,570, 67%), varying by ethnicity: African American (10,223, 38%), Hispanic/Latino (7,425, 28%), and white (7,390, 28%). Twenty-four percent (9,578) of diagnoses were due to heterosexual contact; 19% (7,529) of women received diagnoses, with infection primarily due to heterosexual contact (6,541, 87%) and injection drug use (939, 12%). Overall, 9% (3,425) of HIV diagnoses were attributed to injection drug use.[6] The epidemiology of HIV transmission has changed over time, and infection rates are higher among young people, aged 20–29, who represented 37% (14,740) of individuals diagnosed in 2016. Disparities in HIV prevalence and treatment exist, with African American populations bearing a disproportionate HIV disease burden relative to Hispanic/Latino and white populations.[6]

HIV affects all organs of the body, and PLWH still die from HIV/AIDS. However, we know that today, with increasing survival rates, PLWH are more likely to die from non–AIDS-defining conditions (i.e., non-HIV/AIDS illness) than from HIV/AIDS. Although any chronic, potentially life-threatening illness is challenging for the individual, HIV may lead to additional stresses due to its social stigma. HIV infection has no social, economic, ethnic, or class boundaries, but perceived associations with marginalized or low-income life styles and fears of a potentially life-threatening condition may add stigma and additional stressors for the patient with HIV.

As with other chronic conditions, palliative care provides comprehensive treatment of the physical, psychological, and spiritual aspects of illness and management of symptoms. Ideally, palliative care begins at diagnosis of a chronic illness and continues throughout the trajectory of the disease.[8] This chapter identifies directions for the provision of palliative care for PLWH, beginning with identification of the need for palliative care, followed by potential interventions in various phases of coping with HIV. The focus will be limited to palliative care needs within the psychosocial context of HIV. Information on current medical treatment and prevention of HIV is constantly being updated as new research findings become available. Palliative care nurses who plan to work with PLWH are encouraged to enhance their familiarity with HIV and its clinical aspects, history, and current therapies through a variety of resources available to professionals and the public

The Need for Palliative Care in HIV

In the early epidemic, the trajectory of HIV/AIDS most often ended in palliative care, hospice, and death. By the early to mid-1990s, major developments in antiretroviral therapy (ART) had begun the transformation of HIV/AIDS into a controllable medical condition.[1] Pharmaceutical developments did not occur in isolation but were affected by patient activism leading to changes in the conduct of clinical trials to speed drug development.[9] PLWH who may have experienced and survived the terrors and uncertainties of the early HIV/AIDS epidemic may find themselves today facing other chronic diseases of aging.[10–12]

Among the current challenges of HIV is its chronicity and association with other comorbidities resulting in higher risk of mortality and increased symptom burden.[7] Studies have shown that, even with effective medical treatment, PLWH continue to experience both physical and psychological symptoms.[13,14] PLWH may benefit greatly from palliative care from initial diagnosis and throughout disease progression. In a review article focused on identifying palliative care needs from the beginning of recognized HIV illness, Simms and colleagues[15] evaluated and reviewed 34 studies of individuals diagnosed within their first 6 months. The authors chose this time period because of its common usage in research studies that support clinically observed differences between newly diagnosed and those diagnosed longer than 6 months ago.[15] Although studies varied in design, aims, sample size, world geographic area, income level of country, and quality of methodology, these authors were able to identify commonalities in palliative care needs in the early HIV diagnosis period. Key findings were that symptoms were prevalent at initial diagnosis in all dimensions of palliative care needs, including psychological and emotional distress, spiritual well-being, and physical symptoms such as pain, fatigue, itching, and weight loss.[15] These authors concluded that palliative care needs are present and manageable beginning with the diagnosis of HIV but may be overlooked by clinicians. They recommended patient-centered, multidimensional assessment, with early referral to palliative care specialists.[15]

A number of observational studies in a variety of settings in the United States and Canada have documented the needs of PLWH at mid- and late stages of disease, and these show a similarity to the needs of individuals at an early stage of illness. At one large HIV outpatient clinic, researchers noted that patients usually were referred to palliative care when the primary clinician could no longer manage the patients' symptoms.[16] Multidrug-resistant AIDS infection, AIDS-related dementia, progressive loss of function, and uncontrolled symptoms were major reasons for referral, leading the authors to conclude that better integration of primary care, palliative care, and mental health and substance abuse services could improve the care of PLWH.[16] These study findings document the complex needs of PLWH and support a growing advocacy for referral of PLWH to palliative care earlier in the disease trajectory.[16,17]

Others also have noted the greater need for multidisciplinary care and the higher illness burden sustained by PLWH as they reach the later stage of chronicity. Data from one study showed that physical, social, and mental health functioning were important to PLWH but were impacted by disease burden.[18] As PLWH grow older, a greater disease burden leads to lower quality of life (QOL) for individuals.[18,19] Caring for PLWH throughout the disease trajectory involves an understanding of complex interactions of physical and mental health, including cognitive disorders and substance use, as well as social factors (e.g., housing instability resulting from unresolved psychological issues) associated with HIV.[20] Furthermore, the high association of HIV, substance use, and mental health disorders, the so-called *triple diagnosis*, has been well-recognized in the literature.[21] Assessment of substance use and mental health should be a part of the complete assessment of PLWH.

While palliative care nurses alone cannot address all of the complex issues involved in caring for PLWH, they can serve as valuable members of the interdisciplinary team, primarily in the area of symptom management. Palliative care expertise is especially valuable in the management of chronic pain because primary care physicians may be reluctant to treat pain adequately in individuals with a psychiatric or substance use history.[22] In their description of an HIV palliative care clinic embedded within an HIV primary care clinic, Perry and colleagues noted that of 124 first-time admissions to the HIV palliative care clinic, 91% were referred for chronic pain, more than one-third had depression or anxiety, and more than one-half had a history of substance abuse.[22] A history of substance abuse is a risk factor in PLWH for unrelieved pain.[23] Pain is a frequently reported symptom among PLWH, and better systematic assessment and treatment of pain by clinicians is needed.[24] All clinicians should become familiar with the latest guidelines for management of chronic pain in PLWH.[25] These guidelines provide evidence-based recommendations for treatment of chronic pain in PLWH in a variety of patient situations (see Table 41.1).

Table 41.1 Management of chronic pain in people with HIV: Summary of content of guidelines

Screening, initial assessment, general approaches to management, and management approaches at end of life (I, II, III)
Nonpharmacological treatments (IV)
Pharmacological treatments for chronic neuropathic and non-neuropathic pain (V)
Opioid treatment for chronic non-neuropathic pain; assessing potential negative consequences; safeguards, and minimizing adverse effects of opioids (VI, VII, VIII, IX)
Prescribing controlled substances in the presence of a history of substance abuse; management of individuals undergoing pharmacological treatments for opioid use disorder (X, XI, XII)
Instruments for mental health screening (XIII)

Source: From Bruce RD, Merlin J, Lum PJ, et al. 2017 HIVMA of IDSA clinical practice guideline for the management of chronic pain in patients living with HIV. *Clin Infect Dis*. 2017;65(10):e1–e37. (Roman numerals denote number of guideline.)

Another important type of symptom cluster prevalent in PLWH is that of HIV-associated neurocognitive disorders, also referred to as "HAND." A pathological feature of HIV infection is the potential for cognitive impairment. Tedaldi and colleagues[26] reviewed the relationships among HIV infection, cognitive impairment, and physical and social comorbidities. They noted that cognitive impairment in PLWH can be due to many overlapping causes, both physical and psychosocial. Examples of physical effects on impairment include the HIV disease process, effects of medications, cardiovascular disease, hepatitis C virus (HCV) coinfection, sleep disorders, illicit drug use, depression and other mental illness, and the aging process.[26] The authors also describe possible systemic inflammation, biomarker, and cellular level factors that may be associated with HIV cognitive impairment. They note that social factors related to the physical assessment of HAND may include poverty and low literacy if the individual comes from a disadvantaged educational background. Having a low-income or marginalized lifestyle and exposure to trauma often related to poverty may lessen an individual's resilience and add to physically adverse effects on cognition.[26] The palliative care nurse should be aware of the potential for cognitive disorders in PLWH and their impact on the comprehensive care needs of the patient.

Multimorbidity and Aging with HIV

As length of survival with HIV increases, PLWH experience a more rapid physical aging process due to long-term effects of ART and cellular-level changes of inflammation and immune system damage.[11] In the ART-era literature, 50 years was generally considered the age of an "older" adult with HIV.[27] But many PLWH are living beyond age 50 and are likely to experience significant impacts on their health as HIV-related pathologies and the aging processes coincide.[28]

One of the greatest challenges of caring for the older patient with HIV is managing the chronic illness burden of multimorbidity, with many individuals having two or more chronic conditions. PLWH older than 50 years are likely to have one or more health problems in addition to HIV.[18] Types of comorbid conditions reported by PLWH commonly include hypertension, chronic pain, hepatitis, arthritis, diabetes, neurocognitive impairment syndrome, malignancy, cardiovascular disease, renal failure, bone disease and fractures, liver disease and frailty.[10,11,18,19]

Like other aging individuals, older PLWH are at risk for the development of geriatric syndromes. Rather than focus on a single disease, geriatric syndromes focus on the impact of multimorbidity on outcomes related to the ability to function in activities of daily life and to maintain independence and QOL.[10] Such syndromes are associated with multiple physical, psychosocial, and environmental factors and include function-related impairments such as frailty, sensory and/or cognitive deficits, falls, urinary incontinence, and depression.[12] In a study of geriatric syndromes in 155 older PLWH, the most frequent geriatric syndromes found were pre-frailty, difficulty in activities of daily living, cognitive impairment, and depression.[12] Managing geriatric syndromes is important to decrease age-related complications. Treatment and prevention of comorbid conditions and exercise and diet to control and maximize function and reduce inflammatory influences on aging have been recommended to decrease adverse effects of aging and geriatric syndromes in older PLWH.[10,29–32]

Living and Coping with HIV

A diagnosis of HIV can be devastating for an individual. Even if a person suspects HIV infection, the confirmation may come as shock. Newly diagnosed individuals may have difficulty accepting the diagnosis and delay initiation of treatment. Or they may have difficulty with adhering to a medication regimen or dealing with the emotional and psychological struggles of having HIV.[30,31] In contrast to situations of the newly diagnosed, many long-term HIV survivors have come to terms with their life-long HIV infection. Knowledge of how PLWH have positively coped with HIV over the long term may provide examples of coping strategies for other patients who must deal with the burdens of HIV infection.

A qualitative, in-depth interview study of 16 long-term survivors of HIV/AIDS described how these individuals coped and what positive traits and characteristics were helpful to their survival.[31] Time from diagnosis ranged from 8 to 26 years, with a mean of 17 years; age ranged from 38 to 67 years, with a median of 50 years. Thirteen (81%) were male. Based on this study, three categories of positive coping strategies (disease coping, practical coping, and emotional coping) and a context of social support were elicited from individual patient interviews.[31] Elaboration on the dimensions of coping and social support and their key representative qualities (Table 41.2) provides a framework for assessing and addressing the palliative care needs of older adults living with HIV.

These dimensions of positive coping have been experienced or utilized by PLWH at various times throughout the illness trajectory. However, each person has a unique life history. The most effective ways to address patient needs will depend on individual factors: age, health status related to HIV and comorbidities, socioeconomic level, geographic location, and the like.[32] For example, a 67-year-old man with diabetes, hypertension, chronic obstructive pulmonary disease (COPD), and arthritis; on ART for many years; and living on Social Security in a depressed rural area will have different needs than someone living in an urban area where access to medical and social supports is easier to obtain.[32,33] Listening carefully to the patient's story and allowing it to unfold over time will

Table 41.2 Dimensions of positive coping identified by long-term survivors of HIV

Disease coping	Practical coping	Emotional coping	Social support
Clinician–PLWH communication	Reasons for living	Resilience	Family/friends/pets
Medication challenges	Managing disclosure	Religion/spirituality	Support from professionals
Self-management of health	Giving back to others	Manage negative emotions	Peer support, individual and group

Source: From Reference 31.

enable the nurse to see the broader landscape of the individual's coping challenges.

Disease Coping

Disease coping involves the ability to deal with the medical and physiological aspects of HIV.[31] For a person newly diagnosed with HIV, addressing the psychological and emotional trauma of diagnosis may be the first hurdle for the patient. Developing a therapeutic relationship with primary care clinicians may help the patient move toward taking a greater role in his or her own healthcare.[34] For long-term survivors of HIV, having good physician–patient relationships, dealing with their multiple medications, and taking charge of their own health was important.[31] As older PLWH develop other chronic conditions, their diagnosis of HIV may become less prominent for them as they find themselves facing new diagnoses, medications, and treatments.[32,35,36] For patients with HIV and multimorbidity, additional medications are likely to accompany new diagnoses. Sorting out drug names, their target diseases, their dosages, timings, adverse effects, and interactions with other medications may be a significant challenge for PLWH and adds to the complexity of their healthcare.[32,35]

The palliative care nurse's role in disease coping will include support for the patient by communicating effectively and facilitating communication between the patient and multidisciplinary team members. The palliative care nurse may be the first to assess new symptoms or to identify inaccurate usage and other problems with medications. The role of patient educator is especially important but requires humility on the part of the palliative care nurse. Many PLWH who have lived with HIV long term and have successfully coped with the complexities of HIV infection are very knowledgeable about their condition. Learning from patients, as well as educating them, is an important aspect of patient-centered care of PLWH.

Practical Coping

Practical coping means the ability of long-term survivors to deal not only with the demands of everyday life with a chronic condition, but with the unique condition of HIV.[31] Individuals who successfully coped were able to find reasons to continue their everyday existence. PLWH identified children, grandchildren, pets, and meaningful employment as reasons to go on.[31] Ability to manage disclosure of one's HIV status or the outcomes of involuntary disclosure[37] also demonstrated practical coping. Research has shown that PLWH who voluntarily or involuntarily have their HIV status disclosed may risk stigmatization by some but gain social support from others.[37] Some patients choose to remain private to the extent that even closest family members may not know they have HIV, but they may risk accidental exposure during an illness or accident in which their medical history is evident.[38] Other PLWH choose partial disclosure, selecting the individuals to whom they wish to disclose and the timing of disclosure.[31,38]

The term "giving back" was often heard among PLWH and was seen as a component of practical coping.[31] This theme has been noted elsewhere as a component of resilience in aging with HIV.[39] Individuals who had overcome significant barriers in their struggle to survive HIV/AIDS often did so with help from many sources. They often expressed a desire to give back some of the help they received by volunteering to teach, counsel, or help others affected by HIV.[31,39]

The notion of practical coping by PLWH has implications for palliative care nursing. Important to the assessment of mental health of PLWH is understanding what is meaningful for them in their lives. Nurses may need to work closely with HIV social workers to address certain needs. For example, if having a job provides meaning, but the person is unable to find employment or lacks purpose in life, a social worker may be able to provide referrals to agencies or organizations that provide help targeted specifically for PLWH.

Understanding and maintaining confidentiality is essential for all patients but is especially important in regard to disclosure of HIV status due to the potential for stigmatization and discrimination. At the onset of care, the palliative care nurse should discuss with the patient which individuals know his or her status and with whom the nurse is able to discuss, or not discuss, the patient's healthcare. The nurse should take care to prevent an accidental breach of confidentiality that may occur by linking the patient to HIV-associated entities (e.g., a research study recruiting PLWH), leaving phone messages that may unintentionally disclose private information, or using unsecured social media to communicate with other healthcare providers. Furthermore, the palliative care nurse should become familiar with state laws regulating HIV confidentiality and sexual partner notification.

Emotional Coping

Emotional coping was viewed broadly as encompassing resilience, management of negative emotions, and spiritual/religious support.[31] Long-term HIV survivors often described an ability to take in stride setbacks in their health or social situation and continue with their lives. In a different interpretation of similar themes, Emlet and colleagues[39] characterized a concept of resilience in HIV as encompassing themes of self-acceptance, optimism (similar to "managing negative emotions"), a will to live ("reasons for living"), generativity ("giving back"), self-management ("taking charge of one's health"), relational living ("social support"), and independence. Consistency in some of the themes across the two studies, in spite of the difference in geographic locations (Midwest and Western United States), suggests reliability of these findings for older PLWH.

Although Emlet et al.[39] did not identify spirituality/religious support as part of resilience, Slomka et al.[31] found it to be a recurrent theme of positive coping with HIV for some study participants. Influences of spirituality/religious support on health-related outcomes have been addressed frequently in the HIV literature. In a review of 15 studies examining relationships between spirituality/religion and HIV outcomes, researchers identified 10 studies that showed positive outcomes such as increased CD4 count, undetectable viral load, and an association with increased survival.[40] Other studies in the review showed negative effects, no effect, or a mixed effect on HIV outcomes. According to the authors, some study results may have been affected by inadequately clarified concepts such as the meaning of "spiritual struggle" and views of God as either benevolent or harsh.[40] Findings from other studies showed that PLWH who had religious support after divorce or death of a spouse had slower increases in viral loads.[41] Contact with a spiritual advisor was associated with an absence of major depression, and spirituality/religion was beneficial in promoting medication adherence.[42] In another study focused on adherence and actual spiritual/religious practices, researchers associated praying once a day with 90% HIV medication adherence rate.[43] All authors agreed on the need to further clarify relationships between spirituality/religion and HIV outcomes. At this stage of research, say Doolittle et al.,[40] clinicians should neither encourage nor discourage spirituality/religion for PLWH, but try to understand its role in patients' lives.

Discussing spiritual/religious needs of the patient is part of the role of the palliative care nurse. PLWH may have strong spiritual beliefs but may have rejected or feel rejected by formal religion, especially if a religious institution stigmatizes HIV because of associations with illicit drug use or homosexuality. Spirituality/religion assessment by the nurse can help to clarify this aspect of care. In addition to support for spiritual/religious aspects of care, the palliative care nurse can further promote emotional coping by reinforcing patients' attitudes and behaviors that lead to resiliency. The nurse can also help the patient manage negative thoughts by suggesting ways to reframe them into more positive attitudes.

Social Support

PLWH described the importance of having supportive relationships in their lives, with family, friends, healthcare providers, HIV peer support groups, jobs, community-based social organizations, and even pets as part of their social networks.[31,39] In a more nuanced study of social support and HIV, Oetzel and colleagues[44] examined both social support and social undermining and its relation to health-related QOL (HRQOL). They found that social support positively related to QOL and that it was more important for PLWH to avoid negative interactions that undermined perceptions of support (e.g., low-paying jobs, disapproval by family, perceived stigmatization) than to have positive interactions. They also noted that work status was the strongest correlate of socioeconomic status in HRQOL, a finding that could have potential policy implications for funding such services as job training programs.[44] These authors suggest that healthcare providers, through positive, supportive interactions with patients, can help to mitigate some of the effects of social undermining that PLWH may experience.

That support from health providers may counteract some of the effects of undermining of social supports for PLWH is an important finding. Health professionals who work with PLWH may have an enormous impact on how the individual sees himself and his illness. The perception of stigma by PLWH is common and is one of a constellation of factors that can impede access to care.[45,46,47] While stigmatizing social context may be difficult for individual clinicians to change, it is within the role of nurses to educate themselves and engage in civic action to improve social determinants of health.[48] One area of social action might be to examine laws that may be inappropriately harsh and stigmatizing toward PLWH who, because of past drug use and/or felony convictions, may be prevented from obtaining jobs, voting, or otherwise engaging in society as active citizens.

Advance Care Planning and Advance Directives

Although advance care planning (ACP) and advance directives (ADs) are not part of the coping framework just provided, they are part of palliative care and the healthcare provider role. The engagement of PLWH in ACP and/or formal execution of ADs varies. Researchers who studied AD completion rates in a US inner-city hospital learned that 92% of PLWH did not have an AD upon admission, and this number only decreased to 86.3% during admission.[49] Others reported AD completion rates among PLWH at 8.7%,[50] 23%,[51] and 47%[52] compared to the overall US population rate reported as 23.3%.[53]

Hansen and colleagues[54] studied relationships among rates of occurrence of ACP discussions with physicians and PLWH and their association with drug use, experience of pain, and family and physician communication. Discussions of ACP were more likely to occur when patients had good relationships with their physicians, higher rates of chronic pain, family arguments about end-of-life (EOL) issues, and comfort with discussing problems with one's family.[54] These authors note the importance for clinicians to assess patient–family relationships and communications. Patients who have chronic pain and/or conflicts with families over EOL care may be more amenable to ACP discussions with clinicians.[54]

Instead of EOL issues driving the need for ACP as in the early days of the epidemic, peace of mind and documentation of decision preferences now support ACP for PLWH.[55] With relatively low numbers of PLWH engaging in ACP, perceptions of palliative care, hospice, and ACP were elicited by researchers[56] as part of a larger study on palliative care. Twenty-two PLWH who had at least one other chronic condition participated in four focus groups. Findings indicated that individuals were not familiar with the term "palliative care" or the relevance of palliative care to chronic illness. Those who were familiar with palliative care tended to conflate it with hospice care, which was associated with end of life and viewed negatively by a number of participants. Participants also misunderstood the meaning of ACP. When palliative care and its role in chronic illness management and ACP were explained to participants, they expressed acceptance of the concept.[56]

Although healthcare professionals and the general public may equate palliative care with hospice, PLWH (and HIV clinicians) may do so because of the history of HIV/AIDS.[56] Older PLWH and HIV clinicians may have had first-hand experience with the early AIDS epidemic, when medical treatments had not yet been developed, and palliation, hospice, and death was the inevitable endpoint of HIV/AIDS. Palliative care nurses should be aware that wariness in the acceptance of palliative care by PLWH may result from a collective memory of the history of HIV. Additionally, conversations with patients over time may reveal that some may have had conversations with family or friends about EOL care and may have chosen not to execute a formal AD. Nurses should be familiar with the AD laws in their state and encourage patients to reflect on who they would want to make healthcare decisions for them if they became incapacitated.

Case Example: A Patient Recently Diagnosed with AIDS

Ms. R is a 35-year-old, African American, divorced, single mother of a 7-year-old daughter. Ms. R has an MBA and had a well-paying job until she lost it as a result of postsurgery narcotic dependence that led to cocaine addiction. She contracted HIV from a sexual relationship with a male friend, a cocaine user who introduced her to the drug and who was unaware he was HIV-infected. Ms. R had been in drug treatment and sober for 10 months and was otherwise physically healthy. She was working two different jobs, trying hard to stabilize her life in order to regain custody of her daughter, who was under the care of grandparents (Ms. R's mother and father). Ms. R was diagnosed with HIV only 10 months ago, at the time she began drug treatment. Her HIV was under fairly good control with adequate CD4 count and viral suppression. She was having some trouble with adherence to ART due to some adverse medication effects and a fluctuating work schedule. She was dealing with her parents' anger and disappointment in her and with her own anger at herself and her ex-partner who infected her. Although her parents offered some emotional support, her social network deteriorated when she became addicted, and job and family stresses resulted in occasional episodes of depression. Ms. R felt she was young enough to rebuild her social and family life for her daughter. But she wondered whether she could have a "normal" life with HIV: Would anyone want to "date" her? Would she be able to remarry or become pregnant again? Would she live long enough to see her daughter grow up?

Comment

Ms. R was under an enormous amount of stress in dealing with a recent (<1 year) HIV diagnosis, HIV medication challenges, drug treatment, loss of her daughter, possible alienation from her parents, working two jobs, possible social isolation, and concerns about the future. Palliative care assessment and follow-up would involve coordination and collaboration with other health providers. Her current plan might include:

- Assessment of disclosure issues
- Medication review with patient, communication with primary HIV physician, diagnosis and assistance with adherence issues
- Symptom management for stress, anger; an HIV social worker may be able to advise regarding availability of individual counseling
- Assessment for clinical depression; encourage exercise; yoga
- Dealing with concern about future: ensure patient is linked to HIV resources online and in the community (e.g., AIDS Taskforce), peer counseling
- Assessment of family communication; need for counseling of child, grandparents
- Reinforce coping skills (e.g., daughter as "reason for living"), demonstrated resilience in seeking employment; self-management of health with goal of healthy, extended life; assistance in reframing negative thoughts; assess social isolation—suggest decreasing isolation by identifying a monthly group activity (participation in church or peer-support group) if job does not provide social support

Case Study: A Long-Term Survivor of AIDS

Mr. G was a 66-year-old, retired, white, homosexual male, diagnosed with HIV 25 years ago. He had been having an extramarital affair at the time with another man when he became gravely ill with Pneumocystis pneumonia (PCP) and AIDS. With intensive care and ART, he survived. His wife divorced him and gained custody of their two young children, a son and a daughter. His wife prevented him from seeing his children for a time, but as the children grew older he was able to re-establish a relationship with them. Mr. G had endured multiple other losses in his past, mainly a number of very close friends who contracted AIDS during the early years of the epidemic and did not survive. He considered himself lucky to be alive, having lived through a time when an HIV diagnosis meant an individual had no future. His life had not been very easy, but he was resilient. He had had to endure rejection from some family members who, lacking knowledge about HIV transmission, were afraid to associate with him, but he had had a good relationship with other family members. He experienced great anxiety in deciding to tell his children that he was gay and HIV-infected, but they now accepted his diagnosis and lifestyle. He remained physically and mentally active. He visited with grandchildren often and volunteered twice a week at a homeless shelter because he wanted to "give back" some of the help that people had given him over the past years. His HIV had been very stable, but in the past year his doctor had noted higher than normal fluctuations in his blood pressure. He also had chronic osteoarthritis pain, especially in his back and shoulders, that often kept him awake at night. He was unable to take nonsteroidal anti-inflammatory drugs (NSAIDs) due to gastric problems. Because Mr. G had a short history of illicit drug use more than 20 years ago, his physician still was reluctant to prescribe any medication that had the potential to become habit-forming.

Comment

In contrast to Ms. R, Mr. G has had many years to adjust to his HIV diagnosis and to cope with the challenges of living with HIV long term. He appeared to have stable and supportive social relationships and enjoyed meaningful activities. He was beginning to experience some of the comorbidities of aging and could benefit from symptom management. Pain management was complicated, but nonpharmacological therapies such as exercise might be helpful. He might also be at risk for comorbidities associated with HIV and with long-term ART use, as well as depression as a result of the losses in his life. The palliative care nurse would want to collaborate with the HIV team in monitoring Mr. G's symptoms, pain management, and depression risk.

Case Study: A Patient with AIDS and Multimorbidities

Mr. W was a 56-year-old African American diagnosed with HIV 15 years ago. He did not complete high school, dropping out at tenth grade. He had a former cocaine addiction and occasionally used marijuana. He had hypertension, diabetes, chronic kidney disease, anxiety, depression, and dental caries. He had a detectable viral load, but an acceptable CD4 count. He took a number of medications in addition to his HIV drugs. He sometimes skipped his drugs for anxiety and depression because he disliked how he felt when taking them. He also occasionally missed other medications when he ran out of them and could not afford to refill the prescriptions. Mr. W's only income was from disability and occasional odd jobs. He was incarcerated for a time for an offense related to his drug use. He lived in a poor neighborhood of the city and did not like to go out much because of the high crime rate. He did not rent or own a home or car, but had managed to keep off the streets because he stayed with friends or family, moving frequently so as not to burden those who took him in. He occasionally missed his clinic appointments because he had to take several buses to get to the clinic, depending on the time of day, and he sometimes did not have money for the fare. Sometimes he could get a friend to drive him, but his friends often cannot afford the extra gasoline necessary to transport him.

Comment

Mr. W. had a number of difficult problems related primarily to his poverty. His HIV needed to be controlled; he needed access to medicines and the ability to keep clinic appointments, but transportation and drug costs were problematic. His unstable housing situation and possible social isolation put him at risk for disease progression. His dental caries and possible food insecurity put him at risk for poor nutrition, infection, and other pathologies. The nurse could assess whether the patient had a therapeutic relationship with his physician and help him to establish one if lacking. The nurse may be able to provide continuity of care through home visits if the patient is unable to get to a clinic appointment. The team social worker should review Mr. W's situation to see if he is eligible for services to pay for food or medicine, a free dental clinic, or volunteers to help with transportation or to provide activities to decrease social isolation. Because Mr. W had a detectable viral load, he should be advised about condom use to prevent HIV transmission. Once the immediate "disease coping" challenges were addressed, the palliative care nurse/team can continue to assist the patient with other dimensions of coping.

Conclusion

The provision of early palliative care to PLWH is essential to manage symptoms and improve well-being for this challenging population. The palliative care nurse who chooses to work with PLWH can enhance his or her knowledge about the medical, psychosocial, economic, and historical aspects of this complex illness in several ways. Familiarity with clinical guidelines for HIV and chronic pain management[25] will enable provision of evidence-based care for a symptom that is often difficult to manage in this population. Professional HIV/AIDS literature is extensive and offers up-to-date clinical information. Organizations such as AIDS Taskforces can provide information on services for PLWH. Multiple websites, sponsored by government and private foundations, are publicly accessible with current information. Care should be taken to critically evaluate online information because disinformation based on "AIDS conspiracy" theories or denial of scientific therapies also abounds. Literature and films can offer historical views and insight into the "human" side of HIV infection. Numerous books and articles in the popular press, both fiction and nonfiction, are available about special groups such as ethnic and LGBT populations and about the experiences of drug users (Table 41.3). Such documents, films, and literature are not only informative, but also can help the palliative care nurse more fully understand the experiences of PLWH in the promotion of compassionate care.

Table 41.3 Selected resources

The science and global impact of HIV/AIDS
Center for Disease Control and Prevention (CDC): https://www.cdc.gov/hiv/
National Institutes of Health (NIH) – National Institute of Allergy and Infectious Diseases; https://www.niaid.nih.gov/diseases-conditions/hivaids
World Health Organization: www.who.int/hiv/en/
The human side of the early epidemic
Films:
Philadelphia, 1993 (drama)
How to Survive a Plague, 2012 (documentary film)
Dallas Buyers Club, 2013 (drama)
Books:
And the Band Played On. Politics, People, and the AIDS Epidemic by Randy Shilts, 1987 (also a 1993 film)
My Own Country. A Doctor's Story of a Town and Its People in the Age of AIDS by Abraham Verghese, 1994.

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CHAPTER 42

Caring for the Patient with Substance Use Disorder at the End of Life

Peggy Compton, Yu-Ping Chang,
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Key Points

- With the changing face of treatments for cancer and other advanced diseases, patients are living for longer periods of time, which creates new challenges in treating pain and potential addiction issues on a longer term basis.
- Identifying substance use disorder in patients with advanced disease can be challenging, and old conceptions of addiction, such as tolerance and physical dependence, need to be reexamined.
- Patients with advanced disease and comorbid substance use disorder can be challenging to manage but can be successfully treated with careful documentation, planning, and a therapeutic approach.
- Remember that the patient with advanced disease and comorbid substance use disorder may have two conditions in need of concurrent treatment: one of drug addiction and one of pain.

Introduction

Substance use disorders are an endemic disease in the United States, with estimated base rates of 8–10%.[1] Although higher in certain subgroups, its presence certainly impacts all medically ill patient populations and can negatively affect how pain is treated. Despite the fact that national guidelines exist for the treatment of pain disorders including cancer pain, pain continues to be undertreated, even at the end of life. A recent meta-analysis found a high prevalence of pain (66%, CI, 58–75%) in persons with advanced, metastatic, or terminal cancer.[2] In some studies, more than 90% of patients with terminal cancer or other advanced diseases report unrelieved pain.[3–5] Inadequate treatment of cancer pain is even greater if the patient is a member of a racial or ethnic minority, less educated, older, or has mental health comorbidities.[6] Pain undertreatment is particularly likely to be the case in patients with a history of substance use disorder as the primary pharmacologic tool used to treat pain, the opioids, also have a high abuse potential. Stigma and biases associated with addiction can lead to poor pain management, mutual suspicion and alienation, and patient suffering unless adequately addressed. Although advanced illness does not preclude clinicians from practicing universal precautions related to opioid prescription, such as stratifying risks of opioid misuse and monitoring for aberrant drug-related behaviors,[7] clinicians must always remain alert to how conceptions and misconceptions about addiction could ultimately lead to pain undertreatment.

As is clear from current headlines and public health data, opioid use disorder and the misuse of prescription drugs are significant problems in the United States today.[8] However, abuse of any substance leading to a substance use disorder (the diagnostic term for addiction) can complicate the management of pain for patients at the end of life. While specific estimates of the prevalence of addiction in terminally ill patients are limited (see later discussion), evidence supports that substance use disorder is an issue for those with advanced illness, including cancer and hospice patients. Care of terminally ill patients with a history of or an active substance use disorder presents many unique challenges that may include poor compliance with therapeutic regimens, reliance on family caregivers to dispense medications, lack of addiction expertise on the part of providers, overarching tendency to prescribe controlled substances for symptom management, and the perception that addressing substance misuse or abuse in end-of-life (EOL) care is inappropriate. This chapter will provide an overview of the disorder, including definitions and terminology, and review what is known about the prevalence of opioid misuse and diversion in palliative care patients. Current clinical evidence surrounding the intersection of addiction and pain management in terminally ill patients, including assessment, management, and general practice guidelines, will be presented.

Substance Use, Abuse, and Substance Use Disorder

Drug and alcohol use are common behaviors in the United States and thus are not uncommonly encountered in cancer nursing practice, including palliative care and hospice settings. The great majority of persons who drink alcohol or use a psychoactive drug do so within a functional or recreational social context and never develop problematic use patterns. However, with repeated use, some substance users will develop a “substance use disorder”

(SUD), a chronic, treatable, neuropsychiatric disease which brings consequences that manifest in all life domains (health [physical and psychological], family, employment, financial, spiritual, functional, social). As such, SUD can have a significant impact on patient responses to all aspects of cancer and palliative therapy, most notably in the provision of pain care when opioids are used.

In attempting to estimate the prevalence or presence of SUD in patients with advanced diseases, terminology becomes important (see Table 42.1), especially in that lay language describing the disease is notably imprecise. It is increasingly understood that SUD is a behavioral disorder and is not defined by physical dependence and tolerance, which are simply predictable neurophysiologic consequences of repeated opioid use. Reflecting this, in the *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition (DSM-5), tolerance and withdrawal are not counted as criteria for the SUD diagnosis if a patient is taking an opioid analgesic under medical supervision.[9] Not only does confusing nomenclature complicate the effort to distinguish appropriate from inappropriate drug-taking behaviors in patients with advanced disease, it also impedes the communication that is fundamental for proper pain management and medical care.

Alcohol is the most commonly used and abused drug in the United States. In 2016, 136.7 million Americans aged 12 or older reported current use of alcohol, 65.3 million reported binge alcohol use in the past month, and 16.3 million reported heavy alcohol use in the past month. Thus, nearly half of current alcohol users reported binge alcohol use (47.8%), and 1 in 8 current alcohol users reported heavy alcohol use (11.9%). Among binge alcohol users, about 1 in 4 (24.9%) were heavy users. Nicotine was used by approximately 51.3 million people (1 in 5 people) aged 12 or older in 2016, indicating that 19.1% of the population are current cigarette smokers, making it the second most commonly used drug in the United States. The percentage of people aged 12 or older who smoked cigarettes in the past month was lower in 2016 than in 2002–2014, but it was similar to the percentage in 2015[1]; some of this decrease may reflect the use of electronic vaporizing devices for delivering nicotine, such as e-cigarettes. With respect to illicit drug use, an estimated 28.6 million Americans aged 12 or older reported using an illicit drug during the month prior to the survey interview. The most commonly used drug was marijuana, which was used by 24.0 million people aged 12 or older. Following in prevalence, approximately 6.2 million people reported misusing prescription medications at least once in the past month, including 3.3 million people who were misusers of prescription pain relievers. Thus, the number of current misusers of pain relievers was second only to marijuana among specific illicit drugs of abuse.[1]

In 2016, an estimated 11.8 million people reported using heroin or misusing prescription opioid pain relievers in the past month (11.5 million pain reliever misusers and 948,000 heroin users). The most commonly misused type of prescription pain relievers were the hydrocodone products, including Vicodin, Lortab, Norco, Zohydro ER, and generic hydrocodone. An estimated 6.9 million people aged 12 or older misused these products in the past year, representing 2.6% of the population.[1]

These figures characterize rates of use and misuse of alcohol and drugs in the United States but do not reflect the numbers of persons suffering from a SUD. In 2016, approximately 20.1 million people aged 12 or older met the diagnostic criteria for SUD for alcohol or illicit drugs in the past 12 months as specified in the DSM-5,[9] including 15.1 million people with an alcohol use disorder and 7.4 million people with an illicit drug use disorder. Among those with an illicit drug use disorder, the most common disorder was for marijuana (4.0 million people), followed by an estimated 2.1 million people with an opioid use disorder, which includes 1.8 million people with a prescription pain reliever use disorder and 0.6 million people with a heroin use disorder.[1]

Table 42.1 Terms associated with substance use disorders

Term	Definition
Substance Use Disorder (SUD)	The clinical diagnosis of a problematic pattern of substance use behaviors leading to clinical impairment or distress, including the inability to control use, consequences related to use, and failure to meet major responsibilities at work, school, or home. SUDs are categorized as mild, moderate, or severe to indicate the level of severity, and are both preventable and treatable.
Misuse	Use of a prescribed medication for nonmedical use, or for reasons other than prescribed (i.e., altering dosing, route of administration, or combining substances). Misuse may or may not reflect SUD.
Abuse	Misuse with consequences (mild to moderate SUD). Potentially harmful consequences include accidents or injuries, blackouts, legal problems, and risky sexual behaviors.
Physical dependence	A state of neurophysiological adaptation to substance, evident in a drug class-specific withdrawal syndrome upon abrupt cessation, rapid dose reduction, and/or administration of an antagonist. Physical dependence may or may not reflect SUD.
Tolerance	A state of neurophysiological adaptation in which increased amounts of substance are needed over time to achieve desired effect. Tolerance may or may not reflect SUD.
Addiction	A chronic, relapsing, and progressive disease leading to significant impairment in all life domains (moderate to severe SUD).
Pseudo-addiction	Opioid drug-seeking behaviors secondary to inadequate pain control.
Opioid-induced hyperalgesia	A state of nociceptive (pain) sensitization caused by exposure to opioids.
Aberrant drug-use behavior	Taking a medication in a manner that is outside the boundaries of the prescribed treatment plan, such as using multiple pharmacies and prescribers, repeatedly losing medication, or requesting early refills. The presence of these behaviors may or may not reflect SUD.

Source: Adapted from Reference 47.

Substance Use Disorders in Patients with Advanced Diseases

Although substance misuse and abuse and their associated morbidity and mortality are significant problems in the United States, specific estimates of substance abuse in terminally ill patients are limited. Whereas concerns about misuse and abuse of prescribed opioids have mainly been focused on patients with chronic noncancer pain, similar issues have been described in cancer patients and others with life-limiting illnesses. Today, cancer patients live longer, have extended exposures to opioids, and exhibit the same risk factors for opioid misuse as patients struggling with chronic but nonmalignant pain. In general, risk factors for inappropriate use of opioids appear to be the same for cancer and non-cancer pain patients, with a prior history of alcohol and illicit drug abuse being the most consistent predictor of current prescription opioid abuse in patients with pain, regardless of age. Other important risk factors for opioid abuse include family history of substance abuse, history of a mood disorder (e.g., current depression), pain-related functional limitations, current cigarette smoking, history of child sexual abuse or child neglect, involvement in the legal system, and significant psychosocial stressors.[10,11]

One electronic chart review study found that more than 40% of cancer patients receiving palliative care (n = 114) were screened to be at moderate to high risk for opioid abuse as measured by the Opioid Risk Tool,[12] and younger age (16–45) and a history of alcohol or illicit drug abuse were significant risk factors of opioid abuse; furthermore, more than half (62%) of these at-risk patients with a urine drug test (UDT) ordered had at least one abnormal result.[13] A recent chart review of 323 patients seen in a palliative care clinic showed that almost half (46%) of new patients had positive scores on the Screener and Opioid Assessment for Patients with Pain (SOAPP) screening tool,[14] and 15% had a positive Cut-down, Annoyed, Guilty, and Eye-Opener (CAGE) score. Of the less than 5% of visits that included a UDT, 56% had aberrant results.[15] In two separate studies assessing the risk of opioid misuse in patients with heterogeneous cancer types, the authors found that 25–29% of patients were at high risk for opioid misuse.[16,17]

Although few studies have been conducted to evaluate the epidemiology of SUD in patients with advanced illness, reports of opioid misuse among cancer patients have emerged in the literature.[18,19] In an examination of aberrant drug behaviors in cancer patients, Passik and colleagues found in a secondary analysis of a large controlled trial of fentanyl buccal tablet that 17% (n = 1,160) of participants exhibited an aberrant opioid use behavior.[20] However, aberrant behaviors do not necessarily translate into opioid addiction and diversion (see Table 42.1) and may indicate other issues including undertreatment of pain, self-treatment of psychological and spiritual distress, or sleep disturbances.[21–23] A survey of 57 hospice and palliative medicine fellows reported challenging encounters with patients with substance abuse issues, with 77% of fellows having seen at least one such patient, and 29% reporting more than two encounters within the past 2 weeks.[15]

Assessment of Substance Use Disorder in Patients with Advanced Disease

The co-occurrence of a SUD and advanced disease has a negative impact on therapeutic responses and health outcomes. Illicit drug use, actual or suspected misuse of prescribed medication, or actual SUD creates difficulties in the clinical setting and complicates pain management for patients with advanced disease. Effective management of SUD is fundamental to adherence to medical therapy and safety during treatment, including avoiding risks associated with the toxic effects of drugs on body tissues and adverse interactions between illicit drugs and medications prescribed as part of the patient's treatment. Continuous substance abuse may alienate or weaken an already tenuous social support network needed to help alleviate the chronic stressors associated with advanced disease and its treatment.

Therefore, it is important to incorporate substance use screening and treatment into care, and care coordination for both conditions is needed. The first goal of assessment is to determine whether the patient has a history of substance abuse and then to determine whether he or she is (1) actively abusing, (2) is in drug-free recovery, or (3) is being medically maintained (e.g., methadone or buprenorphine) in recovery. Several reliable and valid screening tools for substance abuse are available at www.integration.samhsa.gov/clinical-practice/screening-tools#drugs, including the SOAPP-R[14] and the ORT.[12] Some are generic and used to screen for many types of substance use, while others are used to screen for abuse of specific substance (e.g., alcohol, tobacco, opioids).

In an effort to not offend, threaten, or anger patients, clinicians may avoid asking patients about drug use. There is often the expectation that patients will not answer truthfully. However, obtaining a detailed history of duration, frequency, and desired effect of drug use is vital. Adopting a nonjudgmental position and communicating in an empathetic and truthful manner is the best strategy when taking patients' substance abuse histories.

In anticipating defensiveness on the part of the patient, it can be helpful for clinicians to mention that patients often misrepresent their drug use for logical reasons, such as stigmatization, mistrust of the interviewer, or concerns regarding fears of undertreatment. When taking a patient's substance use history, nurses should use a matter-of-fact approach and explain that drinking alcohol or using certain medications or drugs can influence responses to cancer medications and treatment. It is wise for the nurse to explain that, in an effort to keep the patient as comfortable as possible by preventing withdrawal states and prescribing sufficient medication for pain and symptom control, an accurate account of drug use is necessary.

The use of a careful, graduated-style interview can be beneficial in slowly introducing the assessment of drug abuse. This approach begins with broad and general inquiries regarding the role of legal drugs in the patient's life, such as caffeine, nicotine, and alcohol, and gradually proceeds to more specific questions regarding illicit drugs. This interview style can also assist in discerning any coexisting psychiatric disorders, which can significantly contribute to aberrant drug-taking behavior. As discussed later, once identified, treatment of comorbid psychiatric disorders can greatly enhance management strategies and decrease the risk of relapse. Questions regarding substance use patterns (e.g., onset, frequency, types, amounts, circumstances of use), including current use and the last episode of use, should be explored. Family history of addiction, as well as problems indicative of an SUD in legal, employment, and social domains must be asked. In addition, nurses must take note of obvious signs of intoxication or withdrawal. Other signs of chronic substance use, such as the medical sequelae of abuse (e.g., liver dysfunction, infection), can aid in identification of addicted patients.

With patients who are in remission (on medication-assisted therapy or in drug-free recovery), nurses should ask for how long and under what circumstances they have been in recovery. The primary substance of abuse should be noted, as well as any current relationship with a support/recovery therapy group and/or sponsor. Patients' concerns about exposure to medications with abuse liability (opioids, marijuana, benzodiazepines) over the course of treatment should be explored, with assurance that nonopioid and nonpharmacologic pain management interventions will be offered. For patients on medication-assisted therapy (MAT) who are taking methadone, buprenorphine, or naltrexone for the treatment of opioid use disorder, nurses should note the daily dose the patient receives and, with the patient's permission, initiate contact with the clinic or provider to ensure continuity of care. Patients should be assured that pharmacologic therapy for the treatment of SUD will continue throughout palliative care treatment and will not interfere with the provision of adequate analgesia as needed.

Challenges to Assessment

Case Study: A Patient with Breast Cancer

Mrs. C, a 65-year-old divorced woman with posttraumatic stress disorder related to early life abuse, underwent an uneventful lumpectomy for breast cancer at age 56. Although she responded well to the surgery and chemotherapy, within 3 months of the procedure, she returned to the oncologist's office with significant anxiety related to the recent onset of severe, constant lower back pain. The nurse practitioner on the palliative care team referred her to the pain clinic, and a magnetic resonance imaging (MRI) scan ruled out metastatic disease. The pain was deemed to be of neuropathic origin, exacerbated by a poorly treated anxiety disorder. With significant psychological support, cognitive-behavioral therapy, and psychotherapy, her symptoms became well-controlled with low doses of oxycodone and clonazepam, and her functionality improved markedly. However, upon her retirement at age 63 and change in insurance plan, her pain care was transferred to a new primary care clinician who was concerned about her daily opioid use and initiated a gradual opioid taper. As the taper progressed, Mrs. C's pain became increasingly severe and her anxiety worsened, making it difficult to sleep; she began to increase her use of clonazepam to manage these symptoms. A routine visit to her oncologist during this time revealed a recurrence of her breast cancer, necessitating mastectomy. The original palliative care team assumed management of her symptoms at this time, agreed to continue her opioid prescription, but became concerned about the escalation of her clonazepam use, knowing that, combined, the medications put her at high risk for overdose. With several attempts at a clonazepam taper, Mrs. C reported intolerable increases in pain, thus her opioid dose was increased. A urine toxicology was ordered, and although the benzodiazepine was present, oxycodone was not. When asked, Mrs. C eventually revealed to the palliative care psychologist that she had started skipping oxycodone doses and hoarding them for fear of untreated postoperative pain and that, related to this fear, was considering not undergoing the surgery at all. With reassurances that her postoperative pain would be adequately managed by the palliative care team and the identification of a primary care provider in her insurance network willing to provide ongoing pain medication, Mrs. C was able to return to appropriate and effective patterns of opioid and benzodiazepine use and proceed with the surgery.

Identification of SUD in patients with advanced disease can be challenging related to aspects of the disease process itself, the presence of pain, concurrent psychiatric disorders, sociocultural biases in opioid prescription, and EOL psychological responses. Changes induced by advanced disease and disease treatment can result in alterations in physical and behavioral functioning that may be hard to distinguish from the diagnostic indicators of SUD. For example, addiction-related behaviors may be difficult to discern in a patient who develops social withdrawal or cognitive changes after brain irradiation for metastases. Even if diminished cognition is related to pain medication, this effect might simply reflect a narrow therapeutic window rather than aberrant analgesic misuse. Similarly, the presence of mild mental clouding or the amount of time spent in bed may be less indicative of addictive disease than other behaviors, such as noncompliance with primary therapy or disrupted relationships with physicians, other healthcare professionals, and family members. To accurately assess drug-related behaviors in patients with advanced disease, explicit information is required regarding the role of the drug in the patient's life. Varied and repeated observations over a period of time may be necessary to categorize questionable behaviors properly.

Issues other than SUD should also be considered if questionable or aberrant opioid use behaviors arise during pain treatment. As previously reviewed, there is compelling evidence that pain is undertreated in populations with advanced disease,[3–5] and clinical experience indicates that the inadequate management of pain and related symptoms may motivate aberrant drug-taking behaviors, including so-called *drug-seeking*. For example, "pseudoaddiction," a term coined by Weissman and Haddox, describes drug-seeking behaviors that occur in the context of unrelieved pain, such as obtaining opioids from multiple sources or hoarding medication.[24] A defining characteristic of pseudoaddiction is that the aberrant behaviors cease with sufficient pain relief and control of nociceptive input. A related concept, "chemical coping," first described by Passik and colleagues, refers to patients being motivated to seek opioids to self-medicate spiritual and psychosocial distress,[22,23,25] including symptoms of anxiety, depression, insomnia, or problems of adjustment (including boredom caused by decreased ability to engage in usual activities and hobbies). A Delphi survey of international experts showed high consensus for several warning signs of chemical coping in cancer patients including depression, psychiatric comorbidity, history of substance abuse and alcoholism, and a positive score on the CAGE screening tool for alcoholism.[26] Unfortunately, pseudoaddiction and chemical coping syndromes pose diagnostic challenges as the boundaries of these two syndromes are not readily discernable; nevertheless, each is unique and requires different approaches for effective treatment.[23,26] Although it may be obvious that drug-related behaviors are aberrant, the meaning of these behaviors may be difficult to discern in the context of unrelieved symptoms.

There is good evidence to suggest that patients who are members of an ethnic minority are at greater risk of inadequate treatment of cancer pain. For many years, studies have documented that minority patients receive insufficient pain treatment compared with nonminority patients when being treated for pain caused by a variety of sources.[27–29] While being nonwhite is a risk factor for pain undertreatment,[6] members of certain racial subgroups, such as African Americans, have a disproportionate risk of pain undertreatment in the United States.[30] In one recent study, African

American cancer outpatients reported a higher burden of cancer pain and opioid-related adverse effects. They were also considerably more likely to be prescribed morphine regardless of their renal insufficiency status, and opioid-related adverse effects were partially mediated by the type of opioid prescribed to African American versus Caucasian patients.[31] Minority cancer patients are also more likely to have negative Pain Management Index scores indicating inadequacy of cancer pain treatment relative to the level of their reported pain.[32] Because minority patients with advanced illness are undertreated for pain, they may be at greater risk of being misdiagnosed if exhibiting aberrant behaviors. Clinicians should recognize that there is considerable heterogeneity within cultures and subgroups of patients. Thus, the best way to understand patients' cultural preferences is to directly elicit them from the patients.

Problematic opioid use may also be indicative of a psychiatric symptom or personality disorder, the diagnosis of which has important therapeutic implications. Patients with borderline personality disorders, for example, may impulsively use prescription medications that regulate inner tension or improve chronic emptiness or boredom and express anger at physicians, friends, or family. Psychiatric assessment is vitally important for both the population without a prior history of substance abuse and the population of known substance abusers who have a high incidence of psychiatric comorbidity.[33] On occasion, aberrant drug-related behaviors appear to be causally remotely related to a mild encephalopathy, reflecting confusion about the appropriate therapeutic regimen. These diagnoses are not mutually exclusive.

Clinical Management of Advanced-Disease Patients with Substance Use Histories

As patients face EOL planning, those with a history of SUD have unique needs. The intrapersonal and interpersonal stressors elicited by physical or emotional states, as well as exposure to psychoactive medications (benzodiazepines, opioids), may precipitate craving or relapse. Patients in stable recovery are likely to have good social and family supports in place, but for those with recent or frequent exacerbations of addictive disease, these may be more tenuous. In addition, all patients with this history are likely to face a certain amount of stigma from healthcare providers and others engaged in their palliative care and may receive suboptimal treatment as a result. Although opioid analgesic prescription should always be approached cautiously in patients with a history of addiction, it is not uniformly contraindicated. The degree to which the pain interferes with activities of daily living and quality of life must be balanced with risk for relapse and the effectiveness of nonopioid and multimodal interventions.

Patients with Untreated Addiction: Focus on Addiction Treatment

The most challenging issues in caring for patients with advanced disease typically arise from patients who are actively abusing alcohol or other drugs. For these patients, seeking and using drugs are their priority, as opposed to adhering to or engaging in the palliative care treatment plan. The sleep disturbances, mood states, and functional losses that accompany SUD, in addition to intermittent withdrawal and craving states, can make symptoms, especially pain, difficult to manage. If pain is undertreated, the risk of binging with prescription medications and/or other substances increases for drug-abusing patients.

Opioids should be used judiciously and under tightly controlled circumstances in patients with pain and active SUD, regardless of type(s) of substance abused. Patients meeting DSM-5 criteria for SUD are, by definition, unable to control their use and achieve the goals of optimal functioning and maximal quality of life. Untreated addiction results in impaired function and diminished engagement in satisfying life activities, thus will necessarily result in poor pain outcomes. In many care settings, the ability to provide the comprehensive services necessary to treat patients with both pain and current addiction are lacking. Patients with an active SUD must be referred to formal addiction treatment, thus, it is incumbent upon the palliative care provider to have available a referral network of substance abuse treatment providers willing to collaborate on providing care to patients with advanced illness, pain, and SUD. After referral, the palliative care clinician can continue to work closely with the SUD treatment provider to address pain symptoms and other EOL needs.

Patients who are actively abusing prescribed opioids must be seen more frequently (e.g., weekly, if possible) to allow close monitoring[5] as well as to build therapeutic rapport with staff and afford evaluation of symptom control and addiction-related concerns. Frequent visits allow the opportunity to prescribe small quantities of drugs, which may decrease the temptation to divert as well as provide a motive for not missing appointments. Until adequately treated, opioid prescriptions should be limited in length and dispensed by a family member or member of the healthcare team. Abuse-deterrent formulations should be considered, as should shorter-acting agents which contain less opioid than long-acting formulations. Perhaps most importantly, nonopioid (anti-inflammatory, anticonvulsants) and nonpharmacologic pain interventions should be implemented, including acupuncture, massage, mindful meditation, and distraction. These approaches will concurrently reinforce SUD treatment interventions as well as be useful for managing pain and other symptoms associated with advanced disease.

Patients with Addiction in Remission: Focus on Relapse Prevention

For individuals with addiction in remission, the goal of treatment is the same as for all palliative care patients: to decrease pain and optimize functionality. Indicators of successful pain management include the patient's ability to comply with pain management and palliative care regimens, engage in cognitive-behavioral pain management strategies, utilize positive coping skills to manage stress, and establish better social support systems. As noted, management of comorbid psychiatric complications, such as depression or anxiety, is critical to maximize functionality.

The literature provides evidence that patients with successfully treated addiction can be effectively managed with opioids for pain. For patients with opioid use disorder (OUD), disease remission may include MAT utilizing methadone, buprenorphine, or naltrexone in the context of broader psychosocial treatment. For patients receiving methadone or buprenorphine, it is commonly assumed that the treatment opioid can provide pain relief, however, the duration of analgesic action is shorter than the effects on withdrawal and craving, thus providing incomplete pain control.[34,35] Furthermore, patients on MAT typically have developed some degree of opioid analgesic tolerance and thus may require higher opioid doses to appreciate pain relief.[36,37] In addition, studies have provided evidence that methadone and buprenorphine maintenance patients may, in fact, have heightened pain sensitivity (opioid-induced hyperalgesia) and therefore have a higher opioid analgesic requirement than matched controls.[38,39]

Regardless of the type(s) of substance previously abused, exposure to opioid medications can lead to relapse in patients with a recently or poorly treated SUD. Thus, when providing opioid therapy, the palliative care treatment goals are expanded to include relapse prevention strategies into the plan of care. Relapse is a predictable event in the course of addictive disease and is understood to be a process that does not occur suddenly or spontaneously and is, therefore, preventable.[40] Central to avoiding relapse are learned cognitive and behavioral strategies the patients can employ in the face of high-risk relapse-promoting situations. These include techniques designed to assist the individual in anticipating and effectively coping with high-risk situations and more general self-control approaches designed to reduce relapse risk by promoting positive lifestyle changes. Specific intervention strategies include enhancing self-efficacy by setting achievable behavioral goals and incorporating stress-reduction activities into their daily life, such as exercise or meditation. The overall purpose is lifestyle balancing, which increases self-efficacy across life domains and therefore minimizes the risk of relapse.

Provider Challenges to Clinical Management

Challenging the provision of effective palliative care to patients with SUD is a relative lack of training for palliative care providers on the management of addiction and pain in patients with addiction. A survey of 57 hospice and palliative medicine fellows on their self-perceived competency in caring for patients who misuse opioids found that less than half (47.2%) stated that they have a working knowledge of addiction; a minority (36.8%) believed they knew how to differentiate undertreated pain from addiction, and only 1.4% agreed that their training prepared them to manage opioid misuse.[15] Furthermore, only 21.1% of fellows were satisfied with how they treat symptoms in this population, and the majority felt uncomfortable dealing with issues such as lost or stolen medications.[15]

Furthermore, palliative care and hospice settings lack policies requiring providers to screen for SUD and diversion in patients and their family members. A national survey regarding the management of substance abuse sent to 94 accredited palliative medicine fellowship program directors found that of the directors who responded (*n* = 39), less than half (40.5%) had policies for screening patients for SUD, and the use of a opioid risk screening tool was reported infrequently (32.4%). Even fewer reported having policies to deal with opioid diversion (27%) or screening family members for SUD (16.2%).[41] Despite this, more than half of respondents indicated that substance abuse and diversion was an issue for their clinics, with only 25% indicating substance abuse was not an issue. Less than half (47%) of staff received mandatory training for dealing with substance misuse. A similar survey of 23 Virginia hospice agencies found that less than half required mandatory training on substance abuse (43.8%) or had policies on screening for substance abuse in patients (43.5%); fewer reported policies for screening for substance abuse in family members (30.4%). With respect to potential diversion, far fewer screened for diversion in patients (21.7%) and families (17.4%). Less than one-third had policies in place to guide the use of opioids in patients with a history of SUD (33.3%) or diversion (30.4%).[42]

These data indicate that current practices for screening for SUD and diversion in palliative care patients and family members is inadequate and that education of hospice workers about SUD is equally insufficient. Despite widespread use of opioids and benzodiazepines as the mainstay of therapy for pain, dyspnea, anxiety, nausea, and insomnia in terminally ill patients, policies regarding safe use and best practices remain rare. Few guidelines address substance abuse and diversion in oncology, palliative care, or hospice,[43] and standard screening tools have not been validated in cancer patients. Consensus guidelines addressing substance abuse and diversion for palliative patients are needed to address this growing problem.[44]

General Guidelines

Recently, the Centers for Disease Control and Prevention (CDC) released guidelines for opioid prescribing in chronic pain.[45] The scope of the guidelines included cancer survivors and those beyond active cancer treatment, although patients with terminal disease and those receiving EOL care were excluded. Subsequently, the American Society of Clinical Oncology (ASCO) released its guidelines, which address risk stratification and adherence monitoring in cancer patients, including patients with advanced disease.[46] ASCO noted that many current recommendations are based on expert consensus and that research is urgently needed to generate empirical evidence to support long-term opioid prescribing in patients with chronic cancer-related pain, including those with concurrent substance abuse disorder. Thus, the following guidelines broadly reflect the types of interventions that might be considered in this clinical context and can be beneficial whether the patient is actively abusing drugs or has a high risk for substance abuse.[46,47] The principles outlined assist clinicians in establishing structure, control, and monitoring of addiction-related behaviors, which may be helpful and necessary at times in all pain treatment.

Multidisciplinary Approach

Pain and symptom management is often complicated by various medical, psychosocial, and administrative issues in the population of patients with SUD and advanced illness. The most effective team may include a physician with expertise in pain/palliative care, nurses, social workers, and a mental health care provider with expertise in the area of addiction medicine.

Monitoring for Risk

Patients with more recent history of drug or alcohol abuse, strong family history of drug or alcohol abuse, and those with a history of major psychiatric disorders are at the highest risk of opioid misuse.[46] These risks should be monitored every 2–3 months. Monitoring should include a detailed interview about drug behaviors, checking of the prescription drug monitoring program (PMDP) database for the evidence of doctor shopping, and a UDT.[47] Several monitoring tools are available to clinicians to monitor risk, including the Current Opioid Misuse Measure (COMM),[48] the Prescription Drug Use Questionnaire (PDUQ) and self-report version PDUQ-p,[49,50] and the Addiction Behaviors Checklist (ABC).[51] Note that all of these tools measure aberrant behaviors and behaviors in violation of treatment agreement (such as obtaining opioids from multiple providers, using other illicit drugs, or increasing dose or frequency) and are not diagnostic of SUD.

Use of Written Agreements

Written agreements that clearly state the roles of the team members and expectations for the patient with respect to medication use are helpful for patient education and for identifying signs of relapse.

These agreements typically stipulate that opioids are obtained from a single provider, that they are taken only as prescribed, outline procedures for refills and replacement of lost prescriptions, state the expectation that patients are engaged in SUD and palliative care treatment, describe use of regular and random UDT, and emphasize the importance of safe storage of medications. Basing the level of restrictions on the patient's behaviors, graded agreements should be enforced that clearly state the consequences of aberrant drug use.[52] Additionally, clinicians who are covering for the primary care provider must be advised of the guidelines that have been established for each patient with a substance abuse history to avoid conflict and disruption of the treatment plan.

Setting Realistic Goals for Therapy

Rates of relapse with SUD are high. The stress associated with advanced illness and the easy availability of centrally acting drugs increase this risk. Therefore, total prevention of relapse may be impossible in this type of setting. Gaining an understanding that complete compliance and abstinence are not realistic goals may decrease conflicts with staff members in terms of management goals. Instead, the goals might be perceived as the creation of a structure for therapy that includes ample social/emotional support and limit-setting to control the harm done by relapse.

Evaluation and Treatment of Comorbid Psychiatric Disorders

As previously noted, extremely high comorbidity of personality disorders, depression, and anxiety disorders exist in alcoholics and other patients with substance abuse histories.[33] The treatment of depression and anxiety can increase patient comfort and decrease the risk of relapse or aberrant drug-taking.

Preventing or Minimizing Withdrawal Symptoms

Because many patients with drug abuse histories use multiple drugs, it is necessary to conduct a complete drug-use history to prepare for the possibility of withdrawal not only from opioids, but also alcohol and benzodiazepines. Delayed abstinence syndromes, such as those that may occur after abuse of some benzodiazepine drugs, may be particularly diagnostically challenging because they emerge slowly and can last for extended periods of time.

Applying Pharmacological Principles to Treating Pain

Self-report remains the gold standard on which to prescribe opioids for pain, with the exact dose being individualized to identify a favorable equilibrium between efficacy and side effects. Individualization of the dose without regard to the absolute amount prescribed can be difficult in populations with substance abuse histories[28]; however, foregoing the principle of dose individualization may increase the risk of undertreatment in this population. The ASCO guidelines recommend using no more than one opioid (e.g., no prescription of a second short-acting opioid) in patients with a high risk of opioid misuse. As noted earlier, clinicians should assess the possibility that pain can be adequately managed with nonopioid therapies.[46]

Use of 12-Step Programs

Depending on the patient's stage of advanced illness and functional capabilities, the clinician may want to consider referring the patient to a 12-step program with the stipulation that attendance be documented for ongoing prescription purposes. If the patient has a sponsor, the clinician may wish to contact the patient's sponsor, depending on the stage of illness and individual capabilities, in an effort to disclose the patient's illness and that medication is required in the treatment of the illness. This contact will also help to decrease the risk of stigmatizing the patient as being noncompliant with the ideals of the 12-step program. If the patient is unable to participate in a 12-step program, other psychosocial and/or spiritual team members can provide care that supports sobriety.

Family Sessions and Meetings

As with all palliative care, in an effort to increase support and function, meetings with family members and significant others should be included in the treatment plan. These meetings will allow the clinician and other team members to become familiar with the family and additionally assist the team in identifying family members who may be using illicit drugs (see later discussion). Offering referral of these identified family members to drug treatment can be portrayed as a method of gathering support for the patient. These meetings will also assist the team in identifying dependable individuals who can serve as a source of strength and support for the patient during treatment.

Safe Storage of Opioid Medication

In the current context of the opioid crisis in the United States, the importance of safe storage of these prescribed medications deserves special mention. Improper storage and disposal of opioids increase the availability of these medications for abuse, diversion, and accidental poisoning. Among people aged 12 or older who misused pain relievers in the past year, about half (53.0%) indicated that they obtained the last pain relievers they misused from a friend or relative.[1] Cancer-related pain is one of the main reasons for prescribing opioids. Up to 90% of patients with advanced cancer require treatment with opioids,[52] and those with advanced disease are most commonly treated with high-dose opioids and therefore are a likely source of diversion of these medications into the community. Cancer patients can experience acute, chronic, and/or breakthrough pain and frequently undergo opioid titrations and rotations to help manage pain and opioid-induced neurotoxicity; consequently, they often possess multiple unused or expired opioids.[53]

Limited information is available about the storage, use, and disposal practices of patients receiving opioids in cancer patients specifically. A survey study of 300 cancer patients found that 56 patients (19%) reported unsafe storage, defined as storing opioids in plain sight; 208 (69%) kept opioids hidden but unlocked; and only 28 (9%) locked their opioids. Seventy-eight patients (26%) reported unsafe use by sharing (9%) or losing (17%) their opioids.[54] Overall, 223 of 300 patients (74%) were unaware of proper opioid disposal methods, and 138 (46%) had unused opioids at home. Patients who had a history of positive CAGE scores or illicit drug use were more likely to store their opioids securely but also were more likely to share or lose their opioids.[54] These findings suggest that many cancer patients improperly and unsafely use, store, and dispose of opioids, highlighting the need for patient education and drug take-back programs.

These findings also raise concern regarding family drug diversion; being a familial disease, it is not uncommon to find that relatives of the patient also have a history of SUD. Given significant debility in terminal illness, family members are often administering opioid medications, especially for patients with SUD. Patient education regarding safe use of opioids should include teaching them to avoid exposing family members with SUD to these medications. However, fewer than 20% of healthcare providers address caregiver history of addiction,[41] which can put the impaired family member, who now has regular access to these drugs, at increased risk. Prescribers who work in palliative care settings have a special responsibility to ensure that these medications are not misused or diverted into the community. Diversion can be difficult to detect, but the UDT can provide evidence that prescribed opioids are not being taken by the patient and are perhaps being diverted.

Conclusion

Treating patients with a history of SUD who are experiencing pain from advanced illness is both complicated and challenging because each condition can significantly complicate the other. Patients are living longer with advanced disease and pain concerns. In the current context of the opioid crisis, it is no longer acceptable to justify high-dose opioid therapy for pain in a vacuum without actively and knowledgeably assessing and managing the potential risks of addiction and diversion. The management of pain in a patient who is actively abusing drugs and/or is a member of an ethnic minority is further complicated due to issues of stigma, bias, and cultural differences that may exist. Using a treatment plan that involves a team approach that recognizes and responds to the complex needs of the patient with a history of SUD is the best strategy to facilitate optimal outcomes. Although pain management may continue to be challenging even when all treatment plan procedures are implemented, the health care team's goal should be providing the highest level of pain management for all patients with SUD.

In achievement of pain management goals, patients receiving palliative care are commonly prescribed opioids to treat pain and may have large amounts of controlled substances in their homes. Balancing the mission of pain relief with concerns about SUD and diversion is a difficult issue for palliative care providers. Many providers are not well prepared to screen for these problems in their patients or the family caregivers, and few work in settings with established policies outlining how to care for those with identified problems. Given the enormous public health implications of the increasing rates of opioid abuse and diversion in the United States, it is imperative that the palliative care community takes an active role in addressing the issue in order to provide adequate treatment of pain and other symptoms in patients with life-limiting illnesses.

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CHAPTER 43

Cancer Survivorship

Anne Reb and Denice Economou

Key Points

- The palliative care approach to cancer survivors includes assessment of physical, psychological, social, and spiritual concerns as well as caregiver needs and concerns.
- Rehabilitation services can help to reduce unmet needs because they focus on improving function and managing common symptoms.
- A comprehensive geriatric assessment can inform the survivorship care plan and help to identify supportive care needs of older adults.
- Early palliative care improves quality of life and symptoms and may reduce caregiver burden.
- Additional training in palliative care for oncology nurses will help to address unmet needs and ensure that survivors receive supportive care services.

Introduction

As the number of cancer survivors is rising in response to new therapies and improved detection, people with cancer are living longer. "Cancer survivorship" is a term that includes many different stages along the cancer continuum, and it is difficult to identify the specific needs of cancer survivors based on that singular title. Additionally, the multiple models used to provide survivorship care as well as palliative/supportive care vary widely depending on the available resources in individual settings and communities. This is the challenge that organizations face as they attempt to incorporate palliative care into survivorship care.

Compared to childhood cancer survivors, in adult cancer survivors less is known about the incidence of symptoms and late and long-term effects. Some cancer survivors experience late or long-term effects that are related to their cancer treatment, age, comorbidities, genetics, and possibly health behaviors such as diet and exercise.[1] Palliative care is essential for high-risk survivors with multiple comorbid diseases as well as survivors with significant symptoms and unmet needs. However, suggesting that all cancer survivors be seen in a palliative care consult may not be helpful to either palliative care teams or cancer survivors who have minimal side effects related to their treatment and may be cured of their disease.[2] Understanding those patients with moderate to high risk of developing long-term and late effects of treatment is essential.[2] We use the terms "palliative" and "supportive" care interchangeably in this chapter.

Relationship of Palliative Care to Survivorship

The inclusion of survivorship care into palliative care fits well because the components and goals of care are similar (Table 43.1). Palliative care includes patients with potentially curable disease, while survivorship care can include people living with cancer and symptoms associated with disease and/or treatment.[3] The focus of care for cancer survivors overlaps with palliative care, the goal of which is to improve quality of life (QOL) by alleviating physical symptoms and distress.[4,5] The population of survivors can include those who have completed active treatment for curative intent and are dealing with difficult symptoms related to cancer or its treatment. Others will complete treatment and may experience late effects of their treatments that require a multidisciplinary approach to relieve their symptoms and meet their complicated needs. This population is similar to the chronic disease populations, where symptoms may improve but will never be cured.[3] The survivor population also includes cancer patients living with advanced cancer where their multiple comorbidities and complicated disease path require more aggressive multidisciplinary care to meet their needs.

Specialist palliative care provides services that cancer patients may not have access to in standard oncology care. Survivors' needs are similar to the needs of those who have traditionally been treated in palliative care settings. These needs include dealing with the impact of their disease on activities of daily living (ADLs), physical and psychological symptoms, and caregiver support.[3] The coordination of survivorship care within palliative care/supportive care programs and services can improve care and resources for survivors.

Survivorship Care and Palliative Care Planning

There are unique issues and challenges beginning with early survivorship and continuing through end-of-life (EOL) care. Discussions about palliative care should be included at the beginning of treatment for those at highest risk for long-term side effects and cancer recurrence.[4] The challenge has become categorizing who is at greatest risk for long-term side effects and at the highest risk for recurrence.[6] The focus for meeting the combined survivorship and palliative care needs is related to providing the correct services for the survivors' individual needs and recognizing who would most benefit from palliative care support.[7] This chapter will provide insight into the important symptoms and concerns that impact QOL in cancer survivors' follow-up care. Applying this information to a

Table 43.1 Palliative care domains and applications for survivorship care

Domains of palliative care	Key components/ symptoms in survivorship care	Interventions
1. *Structure and processes of care*: Emphasis on interdisciplinary team engagement and collaboration with patients and families early in the course of disease. Care plan based on values and goals of patient and family. Community resources ensure continuity of care.	Comprehensive assessment using validated tools Patient-reported outcome measures integrated in the electronic medical record when possible Geriatric assessment to identify need for supportive interventions in older adults Communication and care coordination[a]	Refer patients with advanced cancer to interdisciplinary palliative care teams. Outpatient programs should provide dedicated resources to deliver palliative care services to complement existing programs for patients with high symptom burden/ unmet needs. Services may include nurse navigation, advanced practice nurse-led programs, geriatric oncology, pain, rehabilitation, behavioral health/social workers, chaplains, integrative providers. Convey recommendations and care plan to the primary care physician.
2. *Physical aspects of care*: Interdisciplinary team approach; assessment and treatment of symptoms using validated tools. Manage symptoms with pharmacological, interventional, behavioral, and complementary therapy interventions. Referrals to appropriate specialists.	Fatigue, pain, sleep disturbance, physical function, bowel/bladder issues, cognitive issues, sexual function, nutrition Educate family and other healthcare providers on symptom management and provide resources for urgent needs.	Emphasis on nonpharmacologic approaches, behavioral interventions, complementary therapies. Short-term use of drugs if necessary or in conjunction with nonpharmacologic approaches. Referrals to rehabilitation services (physical therapy, occupational therapy, physiatrist). Self-management approaches to symptom management.
3. *Psychological and psychiatric aspects of care*: Collaborative assessment of psychological concerns; interventions based on patient and family goals of care. Grief and bereavement program for patients and families.	Distress, anxiety, fear of recurrence, depression, adjustment, mood, grief and loss; body image Concerns about family members' risk of cancer; family distress	Normalize referrals to social work/behavioral health. Provide palliative care support for family caregivers.
4. *Social aspects of care*: Interdisciplinary assessment and collaboration with patients-families to identify strengths; promote goals. Comprehensive assessment including family roles, communication, and decision-making patterns. Provision of emotional and social support	Roles and relationships Family, social support Work issues, finances Interdisciplinary team includes social worker	Referrals are made to social work, financial counselor. Facilitate patient and family coping with illness and grief including education and family meetings. Interventions support family structure, values, goals, and preferences.
5. *Spiritual, religious, and existential aspects of care*: Interdisciplinary team including chaplain to assess and manage spiritual issues of patient and family	Meaning, purpose in life, hopelessness, forgiveness, grief, guilt	Referrals are provided to chaplain, spiritual leader. Spiritual/religious rituals are honored. Promote spiritual and religious practices of patient and family.
6. *Cultural aspects of care*: Culture as source of resilience and strength for patient-family. Use plain language, tailor communication to health literacy.	Interdisciplinary team assesses cultural identification, strengths, and needs of the patient and family and tailors the plan of care.	Plan of care addresses patient–family's cultural concerns/needs Communicate and use written materials in preferred language. Identify referrals and community resources that serve various cultural groups.
7. *Care at the end of life*: Team communicates symptoms of dying process to patient and family. Team manages symptoms and provides care to meet physical, psychosocial, spiritual, and cultural needs of patient and family.	Hospice on-board; preparations for death Intensive assessment and management of pain and other symptoms Spiritual grief assessment for family including hopes, fears, and concerns about dying process Develop post-death bereavement plan	Provide guidance to family about what to expect in dying process and post-death period. Healthcare team member is assigned to support the family to assist with religious or spiritual practices, funeral arrangements.
8. *Ethical and legal aspects of care*: Assists with advance care planning, financial issues, ethics, and legal aspects of care.	Advance care planning and ongoing discussion about goals of care Completion of advance care planning documents: DNR orders, advance directives, or living wills Care plans and preferences are documented and communicated when patients transition from one care setting to another.	Educate patient and family about advance care planning. Designate surrogate decision-maker

[a] Communication and care coordination applies to all palliative domains and survivorship components.

Source: Based on information from *Clinical Practice Guidelines for Quality Palliative Care*, 3rd ed., National Consensus Project; References 4, 5, and 11.

case study will help illustrate these principles for integrating palliative care in the cancer survivor trajectory.

Common Concerns of Cancer Survivors

Early palliative care for cancer patients improves QOL. Although many of the same principles apply, the approach to palliative care for cancer survivors likely to be cured of their cancer differs somewhat from those with advanced or metastatic disease.[4] Cancer survivors are living longer as a result of treatment advances, and there is more uncertainty regarding prognosis and future needs. Although many survivors will be cured or in remission for extended periods, they may need support to manage long-term side effects and fears of recurrence.[3] Palliative care referrals should be based on patient and caregiver needs rather than on prognosis, and the focus of support and care planning should be tailored to address their concerns. Survivors are often concerned about recurrence and managing uncertainty, including understanding the meaning of symptoms and whether they may represent disease recurrence.[4,8] They frequently experience troubling side effects, which may persist during the early survivorship period or the side effects may become chronic. Common symptoms may include fatigue, sleep disturbance, neuropathy, pain, and anxiety. Data from the Livestrong Surveys assessed posttreatment concerns and receipt of care for a large heterogeneous group of cancer survivors within 5 years of diagnosis.[9] More than half of the respondents reported physical concerns including fatigue and cognitive problems and one-third reported problems with sexual function, neuropathy, or pain. Eighty percent reported fear of recurrence, and more than 60% reported grief, identity issues, or emotional distress. Fifty percent reported concerns about body image or family members' risk of cancer. In the 2010 survey, survivors reported that they received care most frequently for their physical concerns; they reported receiving care less frequently for emotional and practical concerns (45% and 44.2%, respectively). Women, younger survivors, and those who received chemotherapy plus surgery and/or radiation reported more physical and emotional concerns.[9]

The palliative care approach to survivors begins with an assessment of physical, psychological, social, and spiritual concerns. Psychosocial stressors and emotional issues may contribute to physical symptoms,[4] so it is important to do a comprehensive assessment including family and caregiver needs. Symptoms should be prioritized and psychosocial concerns should be managed. Nonpharmacologic approaches should be emphasized, and, if medications are needed, short-term use is preferable to long-term use and the side-effect profiles should be evaluated as they may exacerbate other symptoms.[4] Early palliative care may also benefit caregivers by decreasing caregiver burden and distress. Supportive interventions for caregivers may include telephone coaching by nurses; education in symptom management, problem-solving, communication skills, and self-care strategies; referral to behavioral health; or in-person meetings.[10,11]

Survivors with advanced cancer or high symptom burden should be referred to interdisciplinary palliative care teams. There is strong evidence that early palliative care improves QOL, depression, and satisfaction with care. During the early survivorship period, outpatient programs often address high symptom burden or unmet needs through models such as nurse navigation, geriatric oncology, pain services, and social workers and transition patients to palliative care programs in later phases of care.[11] Outpatient programs should have dedicated resources to deliver supportive services to complement usual oncology care.[11] There is a need for additional training of oncology clinicians in palliative care skills to address some of the barriers to accessing early palliative care in the outpatient setting.[11]

Although it is unclear which care delivery model is best to meet the growing needs of cancer survivors, rehabilitation interventions can be effective in improving function and managing symptoms such as pain and neuromuscular and cognitive deficits. Rehabilitation needs of survivors whose cancers are likely cured may be overlooked,[12] and referrals to rehabilitation services are underutilized.[13] Referrals to physiatrists, physical therapists, and occupational therapists may help to reduce unmet needs in cancer survivors.[12] An overview of some common symptoms and assessment strategies will be presented in the following sections, including physical, psychological, social, and spiritual concerns. Unique considerations for older adult survivors will be highlighted because almost half of cancer survivors are 70 or older.[14] Communication challenges and an overview of nonpharmacologic approaches to symptom management will be discussed as key considerations that impact survivorship and supportive care.

Case Study: A Cancer Survivor

Marie Lacosta was a 65-year-old female with Stage III ovarian cancer who completed chemotherapy and presented for her 3-month follow-up visit. The patient reported some worsening of neuropathy in her hands and feet and difficulty with walking secondary to pain and numbness. Marie had seen an interventional pain specialist in the past but had not followed up with him recently. Additional symptoms included difficulty sleeping, fatigue, and anxiety. She had a history of diabetes, depression, and anxiety and had been followed by a community-based psychiatrist in the past. Marie was a poor historian and did not recall all of the multiple medications she was taking. For example, her pain specialist was unaware of her past history, and there were medication overlaps.

The patient's husband, Paul, was her primary caregiver. Paul had complained that all Marie does is sit by the window and watch TV all day. She had been an active person who did cycling and attended a gym regularly in the past. She had been depressed about the changes in her body and her fatigue level. She was questioning her faith and felt unable to get back to her normal life. She was also inquiring about supplements that her friend recommended for anxiety and neuropathy.

Common Symptoms and Assessment Strategies

Fatigue. One-third of cancer survivors may continue to experience fatigue following treatment, and it is often undertreated.[15] Cancer-related fatigue (CRF) may occur as an isolated symptom or as part of a symptom cluster including depression, pain, menopausal symptoms, and sleep disturbance.[16] Fatigue may be exacerbated by metabolic and endocrine conditions such as hypothyroidism and adrenal insufficiency. Other contributing factors may be cardiac or pulmonary dysfunction, anemia, emotional distress, nutritional deficits, inactivity, and medications. Furthermore, disruptions in circadian rhythm and the hypothalamic-pituitary-adrenal (HPA) axis, immune dysregulation, and inflammatory cytokines may contribute to CRF. Cancer survivors should be routinely assessed for fatigue using brief screening measures such as the Brief Fatigue Inventory,[17] PROMIS fatigue, or other measures that include a fatigue subscale or single item.[16] The National Comprehensive Cancer Network (NCCN) provides guidelines on cancer-related fatigue posttreatment.[18] Referrals to physical and occupational therapy may be helpful to assist with energy conservation and activity recommendations. These services seek to improve function and QOL, and reduce risk of falling.[13]

Neuropathy. Patients with cancer are at risk of developing neuropathy related to cancer, its treatment, and comorbidities. Chemotherapy-induced neuropathy (CIN) can persist into survivorship and negatively impact functioning, QOL, and fall risk.[19,20] CIN can result in sensory and motor impairment; the most common symptoms include numbness and tingling in the fingers and toes; sensitivity to cold; burning, shooting pain in the toes and feet; and muscle weakness.[21] In a recent study of 512 women cancer survivors, nearly half continued to experience neuropathy symptoms many years after completing chemotherapy, and those with persistent symptoms reported poorer functioning and nearly twice the rate of falls compared with those without symptoms.[20] Increasing symptom severity is associated with worse functioning, increasing disability, and falls. These findings support the importance of early detection and treatment to limit symptom progression and functional decline and referral to rehabilitation services for strategies to reduce the risk of falls and disability.[20] Nonpharmacologic approaches are increasingly being recommended. Research is now focusing on lifestyle factors including exercise, diet, supplements, and natural products for reducing or preventing CIN.[22] The NCCN and the American Society of Clinical Oncology (ASCO) have published guidelines on the management of CIN in adults with cancer and cancer survivors.[23,24]

Distress. Many survivors experience emotional distress that ranges from normal feelings of vulnerability and fear of recurrence to significant depression, anxiety, and posttraumatic stress symptoms. Symptoms of anxiety and depression often overlap with other concerns such as cognitive difficulties and fatigue.[25] Fear of recurrence is common in adolescent and young adult (AYA) cancer survivors. A large cohort study of AYAs at least 5 years from initial diagnosis found that they reported more distress than the comparison group. Furthermore, many of the survivors had not seen a mental health professional in the past year and were more likely to report that they could not afford mental healthcare services.[26] Fifty percent of colorectal survivors in a large national survey reported fear of recurrence.[27] Factors associated with fear of recurrence included being female, of a younger age, from deprived areas, having received chemotherapy, and more recent completion of therapy. Survivors with lower levels of physical activity and current smokers were more likely to experience fear of recurrence.

Depression is common in cancer survivors and may be underdiagnosed, especially in older adults.[13,28] Other conditions that increase susceptibility to depression include thyroid dysfunction, anemia, polypharmacy, social isolation, functional dependence, and altered neurotransmitters. The clinician should provide reassurance about the patient's concerns, manage polypharmacy, examine possible contributing disorders and symptoms, and refer to supportive care if needed.[28] The identification of depression and distress may be improved with the routine incorporation of patient-reported outcome assessments. The NCCN has guidelines for screening distress.[29] Screening instruments may include the NCCN Distress Thermometer, the Hospital Anxiety and Depression Scale,[30] PROMIS instruments, and the Patient Health Questionnaire (PHQ-4).[31] Furthermore, the incorporation of a comprehensive geriatric assessment (GA) in follow-up visits may help to identify older survivors with depression and other unmet needs.

Comprehensive Geriatric Assessment

The Cancer and Aging Research Group (CARG) (http://www.mycarg.org/) recommends that survivorship care plans be tailored to address functional needs of older adults, including exercise, nutrition, polypharmacy, social support, and comorbidities. Research priorities include using a GA to outline health concerns, evaluating best models of care, and partnering with caregivers in care delivery.[32] Research supports that older adults are less likely to receive palliative care and may have different triggers for initiating palliative care; some may include frailty, functional dependence, cognitive impairment, distress, and caregiver problems.[33] It is important to assess and manage comorbidities and polypharmacy in addition to cancer-related side effects. Polypharmacy is common and can lead to poor adherence and adverse drug reactions.[34] A GA should be conducted to determine health concerns and guide treatment decisions and supportive care interventions.[13,35] This assessment typically evaluates functional status, comorbidities, cognition, social, psychological, depression, nutrition status, and polypharmacy.[36] If multiple disciplines conduct the GA, a comprehensive assessment may take 1–2 hours. However, Hurria and colleagues have shown that a computer-based GA provides a time-efficient method to collect data and includes a built-in algorithm for reporting results to clinicians and managing patients.[37] Since time constraints are often an issue in most settings, an abbreviated GA can be administered focusing on the most important needs and other tools can be administered at future visits.[38]

Unfortunately, GA has not been routinely implemented in oncology settings.[32] Incorporating a screening instrument may be useful to identify patients who are likely to have an abnormal GA and require further assessment.[38,39] The G-8 screening tool assesses multiple domains of the CGA and is useful for identifying patients who need a comprehensive assessment.[40] When a GA treatment plan is done, nurses should facilitate referrals to specialty services and followup with patients to assess adherence to recommendations. Communicating the plan to the primary care provider is essential to support adherence.[38] Advanced practice nurses have been proactive in identifying psychosocial issues and other needs of older cancer survivors.[41] Identifying patients at high risk for complications (e.g., high symptom burden, distress, and polypharmacy) is a proactive way to anticipate who may benefit from early palliative care consultation.

Case Study: A Cancer Survivor (continued)

During the initial follow-up visit after completing treatment, Marie reported significant physical, psychological, and spiritual symptoms and concerns. A brief GA confirmed significant neuropathic pain, increased risk for falls related to balance issues, and polypharmacy. The nurse practitioner (NP) asked Marie what was bothering her the most and she replied, "the pain in my feet keeps me awake at night." The NP recognized that the pain is likely influencing other symptoms, and she is concerned about the overlapping medications and her increased risk of falling. The NP contacted the pharmacist for a medication review and also notified Marie's psychiatrist of the overlapping medications. The NP placed an expedited referral to the pain specialist to evaluate the neuropathic pain and a referral for occupational therapy to assess balance and home modifications to reduce the risk of falling. The NP scheduled a follow-up appointment to address her other symptoms and asked Marie to bring all her medications to her subsequent appointments.

Social Considerations in Cancer Survivors

The social well-being of cancer survivors includes social functioning related to roles and relationships and financial and work-related aspects, as well as family concerns.[11] The intrinsic social needs of cancer survivors change over the course of their disease from diagnosis to long-term follow-up.[42] Treatment-related effects for the most part improve once treatment is completed, but other elements within this domain may become more problematic as time goes on. Work- and insurance-related issues may arise as treatments are completed and require referral to appropriate social services to assist with those needs. Family needs also change as treatment ends, as much of the task work of receiving and completing treatments is completed. Changes in the roles of not only the patient but also the caregiver can become problematic at this transition period. Roles may have shifted; patients may be trying to gain back their independence and resume work while still dealing with loss and residual symptoms. Caregivers may be uncertain of their roles and how to best help the survivor.

Work-related issues as perceived by nurse navigators found that the primary issues cancer survivors experienced were related to financial burdens (81%), conflicts between work and treatments (48%), and the need to take unpaid leave to receive care (48%). Only 17% of the navigators who participated in this study found no employment-related issues in their populations.[43] A needs assessment conducted in a cross-sectional convenience sample of more than 1,000 cancer survivors found significantly moderate to high concern responses related to finances and medical costs. This dropped to nonsignificant levels in survivors who were 2–5 years posttreatment. Additionally, moderately to highly concerned fears of recurrence or developing a second cancer dropped to nonsignificant levels after 5 years posttreatment.[42] The social domain is impacted by comorbidities, unrelieved symptoms, and financial concerns that contribute to decreased QOL. Applied to the case study, Marie's experience will help demonstrate the social domain and some of her social concerns may have some overlap with her spiritual and existential symptoms.

Case Study: A Cancer Survivor (continued)

At 3 months posttreatment, Marie was experiencing multiple symptoms that contributed to her feelings of depression, fatigue, and anxiety that severely impacted her social functioning. The symptoms of unrelieved pain and its influence on sleep problems, fatigue, and resulting depression demonstrated the importance of early assessment and management of symptoms during the initial posttreatment phase of survivorship. Lack of management of these key symptoms over time resulted in chronic symptoms that impeded Marie's ability to return to her pre-cancer social functioning. Her symptoms also impacted her relationship with her husband and primary caregiver. These unrelieved symptoms negatively impacted psychosocial functioning over time. For Marie, prioritizing her psychosocial symptoms and assessing their impact on physical symptoms was essential. A priority for her care was pain relief, so she could start to resume some of her usual activities. The NP discussed her concerns with Marie and asked if she would be willing to speak with a social worker with experience in survivorship care. She also spoke with Marie's husband about how he was coping and mentioned that counseling was available for him if desired. Assessing and providing psychosocial support for both Marie and her husband may be helpful to promote communication and well-being for them as a couple.

Spiritual and Existential Influence in Cancer Survivors

Spirituality has been shown to be an important part of the sense of QOL in patients experiencing cancer.[44,45] Examples of spiritual or existential concerns that arise for survivors include questioning the meaning of their illness or life purpose and dealing with grief, loss, and anger, as well as positive outcomes such as forgiveness and gratitude. People experiencing cancer have described the importance of spirituality in their ability to cope with their illness and strengthen their feelings of hope, meaning, and purpose of their life.[44] Spirituality is conceptualized as including three components: meaning, peace, and faith.[46] In a study done by Davis and colleagues (2017), spiritual well-being was examined longitudinally to describe its impact on emotional outcomes in ovarian cancer patients. Spirituality had a significant impact on positive well-being in ovarian cancer survivors 1 year post diagnosis. Lower depression, anxiety, and total distress was noted in follow-up and greater feelings of peace.[47] The experience of posttraumatic growth (PTG) in cancer survivors impacted positive well-being scores and adds to the importance of supporting spirituality in survivorship follow-up.[45,47] In an effort to improve spiritual well-being and help cancer survivors find meaning in their experience and inner peace, including a spiritual assessment and communicating spiritual support is essential.[45,48] Consideration of cultural issues and beliefs is key to communicating with survivors and families about spiritual concerns.

Cultural studies related to the meaning of spirituality in patients along the trajectory of their cancer illness have identified important impacts on coping and QOL.[49–51] Lung cancer patients described spiritual well-being as contributing to improved psychological well-being and lower symptom distress.[49] Older African American patients with colorectal cancer described the influence that their beliefs had on reducing fear and increasing acceptance of their prognosis.[52] Cultural considerations of the impact of spirituality on cancer survivors influence health behaviors and may help guide intervention choices that would have a greater chance at success. Spiritual beliefs about cancer that are related to a fatalistic belief that God provides divine control over their course of disease can be a barrier to self-management or motivation to change behaviors that contribute to poor outcomes and increased risk for recurrence, such as a healthy diet, increasing exercise, and smoking cessation.[52]

It is important for clinicians to ask about and assess spiritual concerns as research supports that patients would like providers to talk to them about spiritual concerns.

Spiritual Assessment to Meet Survivorship Needs

The FICA tool (*Faith,* belief, or meaning; *Importance* of spirituality; individual's spiritual *Community*; and interventions to *Address* spiritual needs) provides a clinically efficient method to screen for spiritual concerns of patients with cancer and helps provide individually focused care.[53] The Functional Assessment of Chronic Illness Therapy-Spiritual Well-being (FACIT-SP) provides a 12-item tool to measure spirituality with three subscales: meaning, peace, and faith.[46] These tools have been used to assess spiritual well-being and its impact on health–related QOL.[54–56] If spiritual distress is identified, referral to a chaplain or other spiritual counselor is needed for a comprehensive assessment of spiritual concerns.[29]

Case Study: A Cancer Survivor (continued)

Marie reported during her follow-up visit that she was questioning her faith. The nurse listened carefully and asked Marie to tell her more about how she was feeling. Although it may not require an immediate intervention based on the other priorities identified in this visit, including the FICA or a spiritual assessment as part of the survivorship needs assessment posttreatment may help to understand Marie's concerns and determine their impact on other aspects of her life. The nurse asked if Marie would like to meet with a chaplain or minister and Marie said that would be OK. The nurse placed a referral to chaplaincy for a more comprehensive assessment of her concerns. Addressing Marie's spiritual concerns might help her deal with other symptoms she was experiencing and help her find some meaning and peace.

Communication Considerations

Studies have documented the need for improved communication in the early survivorship period regarding symptoms and psychosocial concerns. In a national survey, cancer survivors reported their experience of patient-centered communication with their providers. About half of the respondents reported that providers did not always help them with managing uncertainty or attend to their emotional concerns, and one in three reported that providers did not allow them to ask all of their questions.[57] Various barriers including provider and patient factors, contribute to this communication gap. Clinicians should understand that survivors may use indirect cues in expressing emotional concerns or may not bring up these issues unless the clinician specifically inquires. Nurses should ask open-ended questions such as "Do you have any concerns or worries?" When survivors share their emotions or discuss psychosocial concerns, the clinician should validate their feelings and ask clarifying questions rather than minimizing or changing the topic. Good communication should acknowledge what is known, possible outcomes, and uncertainty.[4] Uncertainty regarding the effectiveness of treatment can be a source of anxiety. Clinicians should clarify the source of the uncertainty, address the anxiety or emotions associated with uncertainty, and offer some coping resources or referrals depending on patient preferences.[58]

Dean and Street (2014) provide a three-stage model to help manage emotional distress, including recognition, exploration, and therapeutic action. Recognizing emotional distress can be challenging as patients may be reluctant to report symptoms and clinicians may not respond appropriately. Active listening, practicing mindfulness, and asking about the survivor's concerns can facilitate rapport and promote discussion of concerns.[59] Acknowledging and validating emotions and being empathetic can encourage the patient to elaborate on his or her concerns. Therapeutic action can involve various strategies to manage distress, including providing information, discussing options to help manage uncertainty, and identifying resources, referrals, or interventions to manage distress. ASCO recently published guidelines regarding communication skills and tasks that are applicable across the cancer trajectory, including various topics such as goals of care, prognosis and treatment, facilitating family involvement, EOL care, and communication skills training.[60] Assessing survivors' information needs and preferences, ascertaining their understanding of the plan of care, and helping them evaluate various sources of information can facilitate patient-centered communication.[61] For example, survivors may have questions regarding lifestyle measures and complementary therapies to manage symptoms, and providing evidence-based recommendations will facilitate informed decisions.

Nonpharmacologic and Integrative Approaches to Symptom Management

Survivors are often interested in learning about strategies to reduce their risk of recurrence and may inquire about nutrition, lifestyle factors, or integrative approaches for symptom management. Obesity is a known risk factor for several cancers and is associated with cancer recurrence, new primary cancers, cancer-related mortality, and the development of comorbidities.[62] Demark-Wahnefried and colleagues provide a review of practical interventions for weight management, physical activity, and diet to promote healthy lifestyle behaviors in cancer survivors.[63] The NCCN survivorship guidelines also provide suggestions for physical activity, nutrition, and weight management.[18]

Cancer survivors frequently use complementary therapies such as imagery/relaxation, yoga, meditation, hypnosis, and tai chi to improve QOL and manage symptoms and side effects of treatment.[64,65] Recent publications review the evidence base for the use of various complementary therapies in cancer care[64,65] and dietary and herbal supplements in survivors.[66,67] Dietary supplements are frequently used by cancer survivors for risk reduction and symptom management. However, studies exploring the effects of supplements on cancer outcomes have mixed findings and outcomes can be influenced by lifestyle factors, type of cancer, supplement dose and formulation, and other factors.[66] Survivors should be encouraged to report any supplements they are taking, and clinicians should discuss the evidence base including possible benefits and adverse effects. The Natural Medicines database (http://naturaldatabase.therapeuticresearch.com/home.aspx?cs=CEPDA~CPCE&s=ND) and the National Center for Complementary and Integrative Health (https://nccih.nih.gov/) provide evidence-based information on natural products and integrative therapies for a variety of symptoms and conditions.

Case Study: A Cancer Survivor (continued)

The NP asked Marie about her lifestyle and physical activity level before she developed cancer and how the cancer has impacted her. The NP also asked if she was currently taking any nutritional or herbal supplements. She asked Marie what supplements her friend recommended and why she thought they may be helpful. The NP stated that she would review the supplements and discuss them further at the next meeting. She planned to ask Marie if she would like a referral to the integrative cancer program to learn more about complementary therapies that might be beneficial for her symptoms. Since Marie had been active and exercised regularly prior to her cancer, the NP also discussed referral to physical therapy for conditioning exercises and recommendations once her pain was under control.

Palliative Care in Advanced Cancer Survivors

The definition of cancer survivor in the United States includes any patient who is diagnosed with cancer, from diagnosis until death. Therefore, survivorship care includes a rapidly growing new population of cancer survivors living with advanced disease.[68] These survivors may be receiving continuous treatment to maintain stable disease or palliative chemotherapy for symptom control. This population poses a significant challenge for palliative care teams as well as survivorship care teams. These patients may be receiving active treatment for multiple symptoms, have follow-up needs that go along with treatment, and additionally are facing the reality of advanced cancer and its probable shortening of their lives. These patients are candidates for palliative care to address symptoms and advance care planning needs. From a palliative care perspective, this population combines the traditional living with chronic disease patient with the reality of advanced-stage cancer and living with stable disease where death is inevitable. This presents a challenge for palliative care teams who can bring symptom management and advance care planning to a population experiencing significant needs and an uncertain illness trajectory. Assessing the needs of this population is essential and requires that palliative and survivorship teams are especially focused on identifying this population as one of highest risk for unmet needs requiring care that supports their needs.[69]

Conclusion

Providing appropriate care to survivors with significant symptom burden or those at high risk for long-term and late effects of cancer and its treatment is a priority. Identifying the survivors who will benefit the most from palliative/supportive care interventions can be challenging. Triggers based on symptom burden and patient and caregiver needs and not prognosis alone is essential. Recognizing that many survivors' highest unmet needs are related to psychosocial concerns can be a starting point for assessment and referrals that can improve care.[9]

Ongoing assessment of symptoms and unmet needs is necessary to identify high-risk survivors as candidates for multidisciplinary palliative/supportive care follow-up. A comprehensive assessment using validated tools should include physical, psychological, social, and spiritual domains and will provide a roadmap to guide supportive care interventions and referrals to appropriate services. Recognizing that survivors and caregivers have different needs along the trajectory of survivorship from diagnosis to death supports the need for ongoing assessment. Survivors who are in transition from active treatment or in remission may benefit from early referrals to rehabilitation services to manage symptoms and prevent long-term effects. Survivors with metastatic or advanced disease recurrence with high symptom burden will benefit from focused assessment and multidisciplinary planning provided by palliative/supportive care teams. Hospitals and community practices should assess their current resources and identify ways to improve or supplement the supportive care services available to their patients. Additional training in palliative care for oncology nurses and clinicians will help to ensure that survivors receive supportive care services especially in areas where palliative care teams are not readily available or are overburdened.

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CHAPTER 44

Veterans

Deborah Grassman

Key Points

- Veterans who served in dangerous duty assignments may have deaths complicated by traumatic memories or paralyzing guilt, depending on the extent to which they were able to integrate and heal traumatic or guilt-inducing memories. This sometimes manifests as agitation at the end of life.
- A high incidence of alcohol and other substance abuse or other "flighting"-type behaviors are often used either to avoid confronting locked-up feelings or to numb traumatic memories.[1] These factors may contribute to "unfinished business" as veterans face the end of their lives.
- *Moral injury*, a subcategory of *soul injury*, may surface at the end of life, resurrecting feelings of guilt and shame that can complicate peaceful dying.[2]
- Veterans often acquire wisdom because they have reckoned with trauma, stoicism, addiction, and soul injury. Understanding these four elements helps access their wisdom and has been referred to as *posttraumatic growth*.[3]
- Veterans and their families have unique bereavement needs to consider when providing care.

Introduction

Military experiences often change veterans in fundamental ways that shape, mold, destroy, and help them find meaning in the rest of their lives and at end of life. There are 1,800 veterans dying every day in America—about 25% of all dying Americans. Only 4% of these veterans die within the Veterans Affairs (VA) medical system. Many of the remaining 96% receive end-of-life (EOL) care in community home or non-VA inpatient hospice programs.[4] Education is needed to inform those working in home and non-VA facilities to help understand the special needs of veterans at the end of life.

Stoicism: Early Indoctrination that Continues at the End of Life

Veterans are often noncomplaining, "grin-and-bear-it" types who endure their sufferings silently. The few times that tears or fears break through their stoic facades, they feel embarrassed, apologize, and quickly retreat behind walls of stoicism; these walls offer protection. Unfortunately, their "fight to the bitter end" attitudes sometimes mean just that—fighting toward a death that is, indeed, bitter. Survival-mode mentality interferes with letting go at end of life.

It is important that clinicians know how to create safe emotional environments. Otherwise, dying veterans will underreport their physical and emotional pain as well as any fear they are experiencing. A clinician's ability to breach a veteran's stoic facade can be important because walls of stoicism might contribute to agitation and lack of peace as veterans die. Stoicism is necessary on the battlefield, as it is in many life situations, but the walls that stoicism erects can outlast their usefulness. The walls keep out necessary feelings—and other people. Although it is important to respect veterans' silence when they choose to maintain stoic fronts, it is also important to offer alternatives. Helping veterans use stoicism like a door instead of a wall can be useful. A door can be opened or closed at will and as often as they want, leaving the safety of their stoicism available to them.

Stoicism might be conceptualized as comprising three components: pride, control, and independence. Inability to let go of pride, control, and independence so that a veteran can reach out for help increases suffering. Physical limitations and emotional displays can embarrass veterans and create fears that others will perceive them as weak. They might feel helpless and vulnerable to attack. Letting go might be viewed as admitting defeat or an act of surrender—something good soldiers do not do. Yet mature mental health includes identifying needs and asking for help when it is needed. Both require vulnerability. Stoicism often keeps people from saying what they need or allowing others to meet their needs. This mask of invulnerability sometimes will not even allow them to admit they *have* needs. This can cause frustration for family members and professional caregivers who desperately want to do whatever they can to help.

Many dying veterans are able to let go of control, allowing themselves to become completely human, growing in humility as they learn how to ask for help and how to become a gracious receiver, discovering connection and compassion in the process. This takes courage, and it is as heroic an effort as facing any enemy in battle. Sooner or later, a veteran's stoic walls have to crumble. Later means fighting to the bitter end; sooner means a weary soldier is finally able to surrender to hope for a peaceful death.

The Culture of Combat

Embedded within the stoic, military culture is another culture: the culture of war.[5] Many soldiers sustained emotional, mental, social, spiritual, and moral injuries that sometimes caused a lifetime of soulful suffering. This suffering might be submerged in the unconscious, but, at the time of death, wartime memories sometimes emerge.

It is important to remember that many veterans who did not serve in a declared "combat zone" have also experienced the consequences of a combat culture. Dangerous missions are required for numerous military assignments. In fact, sometimes the trauma they sustain can be even more damaging because it often goes unacknowledged or is minimized because "I didn't see combat." All veterans have set aside prime years in their lives, delayed personal goals, separated from loved ones, and went to strange and sometimes dangerous parts of the world. They were expected to do difficult jobs that they may or may not have been inclined to perform. All were trained to defend their country and be willing to risk their lives if necessary to do so.

A Combat Subculture: Posttraumatic Stress Disorder

Stoicism permeates military culture, whether a veteran served in combat or not. Combat veterans and others who have served in dangerous-duty assignments have to additionally cope with traumatic memories.[6] For some, the memories crystallize into a constellation of symptoms known as *posttraumatic stress disorder* (PTSD).[7]

Many people with PTSD have successfully coped with their traumatic experiences by learning lessons that help them live their lives, deal with trauma, and reckon with PTSD.[8] If they have received PTSD treatment, they can often say what helps them feel better. They might already have a PTSD network of friends who can provide support. Family members usually know how to respond to breakthrough episodes of PTSD because it is familiar territory.

When patients with PTSD are admitted to a hospital and/or hospice or palliative care unit, they are sometimes anxious, suspicious, or angry. Leaving their home to enter an unknown hospital environment is threatening, increasing their feelings of danger. The hospital environment itself can act as a trigger, with its somewhat militarized processes. Their own anticipated death can act as a PTSD trigger. And PTSD, especially when combined with alcohol abuse or misuse of other substances, has often taken its toll on their relationships, leaving much unfinished business to be resolved so a peaceful death can ensue. Sometimes they arrive at the end of their lives broken, with bitterness poisoning their souls. However, it is never too late. Opportunities for growth abound when death approaches, and many people—even those who are bitter—avail themselves of the lessons.

Interventions: Responding to the Unique End-of-Life Needs of Veterans

Penetrating Stoic Facades

Stoicism is important, even essential, especially on a battlefield. It creates protection from untrustworthy influences. It is the *relationship to* stoicism that might need modification. It can be used inappropriately to block energy and emotion from the self or can interfere with expressing love to others. Stoicism can also contribute to veterans' underreporting their fear, emotional pain, and physical pain. The healthcare provider can help reeducate veterans by offering alternatives for them to consider, such as: "I know a lot of veterans put on a macho front and don't want to take pain medication, but pain can consume your energy. You need your energy for other things now."

Helplessness and losing control are especially threatening: "Sometimes veterans tell me feeling helpless makes them angry. I imagine it's hard for a soldier to learn how to surrender, to let go," or "Some veterans tell me asking for help is humiliating. Tell me how helplessness makes *you* feel."

Creating Environments of Comfort and Trust for Combat Veterans

Veterans might talk about past experiences with death—deaths that were often violent and mutilating. They bring these experiences with them when they are enrolled in hospice programs or admitted to a hospital or community program for palliative care. To allay these fears, it can be helpful to discuss the peacefulness of their expected death and the plan for how that will be achieved.

It can be important to eliminate as many "triggers" for PTSD as possible. Coming into a hospital (especially a VA hospital) can trigger past military memories of barracks, military procedures, unsafe environments, past combat hospitalizations, and visiting injured comrades. Loud or unexpected sounds will startle people with PTSD, and they should not be touched without warning; the clinician should first call the patient's name or make sure that he or she is within their line of sight. The use of bed alarms should be limited; they exacerbate the startle response. Restraints should also be avoided; even tight bed clothes or linens can trigger memories of being confined in prison if the veteran was a prisoner of war.

Trust plays an important role in helping veterans with PTSD because these veterans do not trust easily. They have been taught *not* to trust. In a hospice or palliative care program, trust may need to be gained quickly because the veteran may not have long to live; time to build a trusting relationship is simply a luxury that is not always available. The clinician's movements, tone of voice, and open language become important opportunities to convey trustworthiness. Additionally, people with PTSD will often "test" clinicians to see if they are trustworthy.[9] Thus, dialogues about death should be done openly and directly when a veteran with PTSD is admitted to a hospice program or to a traditional hospital for end-of-life care. These veterans faced death before when they were in combat. In fact, they were required to complete advance directives and wills *whenever* they went into a combat zone, so they are used to an open dialogue about dying.

If the veteran becomes agitated with wartime memories, especially if he is in the last several days of life, the "anchoring heart" technique can support emotional safety.[10] In this technique, the clinician places his or her hand firmly on the veteran's chest or, alternatively, on the back. This is usually very calming because anxious energy usually rises: the voice gets higher pitched and energy gets flighty. A calm, centered person's energy usually resides lower and deeper. If a calm person places his or her hand on an unsettled person's sternum, it can often help the anxious person to feel secure, grounded, less anxious, and safe to feel whatever they are experiencing. (This securing gesture is often practiced *unconsciously* when people get bad news. They will gasp and place their palm over their own sternum to anchor themselves.) Family members can be taught to do the anchoring heart technique with the veteran. It not only helps the agitated veteran, it helps family members with their own sense of helplessness.

Box 44.1 provides resources that can help veterans, their families, and professional caregivers. These resources provide clinicians

Box 44.1 Resources for Veterans, Their Families, and Care Providers

Opus Peace is a nonprofit organization with a mission of providing programs that respond to soul injuries. Additionally, Opus Peace helps communities and agencies provide Fallen Comrade ceremonies to heal unmourned grief and unforgiven guilt that veterans may still be carrying. Go to www.OpusPeace.org or www.SoulInjury.org for more information.

Four Final Life Lessons and *Caring for Veterans* are two booklets available free of charge at https://www.opuspeace.org/Shop.

We Honor Veterans is a program by the National Hospice and Palliative Care organization that provides information and toolkits to provide EOL care for veterans. Learn how to "earn your stars" as an agency that cares about veterans. Go to www.WeHonorVeterans.org for more information.

Soldiers Heart is a nonprofit organization whose purpose is to "alleviate the symptoms of PTSD by developing a new and honorable warrior identity." They also promote, train, and guide community-based efforts to heal the effects of war. Go to www.SoldiersHeart.net for more information.

Hospice Foundation of America's Living with Grief series 2013 focuses on improving care for veterans facing illness and death. Go to www.Hospice Foundation.org for more information on their educational program.

Honor Flight is an organization that flies combat veterans to Washington DC to see their memorial monuments. This program is provided free of charge to veterans. It currently emphasizes World War II veterans, but serves any war veteran nearing the end of life. In subsequent years, it will focus on post–World War II vets. Go to www.HonorFlight.org for more information.

Veterans Families United Foundation (1-405-535-1925) helps veterans and their families cope with the aftermath of war and provides information about accessing benefits. Go to www.VeteransFamiliesUnited.org for more information.

Military One Source (1-800-342-9647) provides counselors 24 hours a day. Go to www.militaryonesource.com for more information.

National Center for Posttraumatic Stress Disorder provides information about PTSD. Go to www.ncptsd.va.gov for more information.

National Alliance on Mental Illness (NAMI) describes various mental health issues affecting veterans. Go to www.nami.org/veterans for more information.

America Supports You is a Department of Defense website that connects veterans with organizations willing to provide services: www.americasupportsyou.mil.

Vet Centers (1-800-905-4675;1-866-496-8838) provide readjustment counseling and outreach services to all veterans who served in any combat zone, as well as services for their family members for military-related issues. Services are provided at no cost. There are 232 community-based Vet Centers located in all 50 states. Go to www.vetcenter.va.gov for locations.

Gold Star Mother provides support for mothers who have had a child killed in the military. Go to www.goldstarmom.com for more information.

Gold Star Wives provides support for wives who have had husbands killed in the military. Go to www.goldstarwives.org. for more information.

A monograph has been written by Larry Beresford about veteran issues surrounding the end of their lives. Read it online at www.va.gov/oaa/archiva/ Va_Transforms_End_of_ Life_Care.pdf.

with tools that will develop their skill and confidence in not only providing care for veterans but also learning principles about EOL care for *anyone* who has been traumatized.

Moral Injury: A Subcategory of Soul Injury

A *soul injury* is an overlooked, unassessed wound that separates a person from his or her authentic self, corrupting their identity and sense of "being."[2] The concept of soul injury applies to veterans and nonveterans, traumatized and nontraumatized, alike. Soul injury can be experienced by victims of sexual assault, crime, accidents, natural disasters, bullying, abuse, and neglect; people who have experienced heartache, loss of personal health or a loved one's health, death of a loved one, or betrayal by a significant other; minorities and marginalized members of a society, culture, or group; and veterans, first responders, and civilians living in war-ravaged countries.[2]

Soul injury is a spectrum of wounds that range from traumatic to insidious. "Traumatic soul injury" might accompany PTSD in veterans if the trauma changed how they perceive themselves. For example, a combat veteran's action or nonaction harms a comrade, he subsequently feels ashamed, and he no longer feels like a person of worth. Less apparent is "insidious soul injury," which occurs more gradually and becomes chronic before it becomes obvious. For example, a veteran has an unfair military administrative action taken against him or is labeled as "weak" when unable to maintain a stoic façade. Over time, this might cause the veteran to feel defective or inadequate—hallmarks of soul injury. Unmourned loss, unforgiven guilt or shame, and diminished self-compassion often keep the soul injury alive throughout a lifetime.

Moral injury is a specialized subcategory of soul injury that is primarily associated with combat veterans. It is especially relevant for veterans as they prepare for the end of life. The term originated with VA psychiatrist, Jonathan Shay. Shay sought a name that could describe the moral damage experienced by veterans during dangerous military assignments. He believed that much of the distress that veterans suffer represents an inner conflict between their moral beliefs and their actions during military service, such as killing children. He called this ethical conflict "moral injury."[11] The term has subsequently been adopted by both the VA and the Department of Defense: "Events are considered morally injurious if they transgress deeply held moral beliefs and expectations."[12]

Experiencing or witnessing violence can be disturbing for anyone, but the difference with veterans is that they also *committed* violence. This might cause a moral injury, as this case example depicts.

Case Study: A Patient with Moral Injury

Jim, a World War II vet, was weak with a cancer that would take his life in a few days. The palliative care nurse introduced herself and asked if there was anything from the war that might still be troubling him. He said there was, but he was too ashamed to say it out loud. Motioning the nurse to come down close to him, he whispered, "Do you have any idea how many men I've killed?" The nurse shook her head, remained silent, and met his Jim's gaze. He continued. "Do you have any idea how many throats I've slit?" The nurse remained silent, but her eyes began to tear, as did Jim's. They remained silent, sitting together, sharing his suffering. No words were needed. This was a sacred moment that words would only interrupt.

After several minutes, the nurse asked, "Would it be meaningful if I said a prayer asking for forgiveness?" Jim nodded. The nurse placed her hand on Jim's chest, performing the anchoring heart technique and said: "Dear God: This man comes before you acknowledging the pain he has caused others. He has killed; he has maimed. He hurts with the pain of knowing he did this. He hurts with the pain of humanity. He comes before you now asking for forgiveness. He needs your mercy to restore his integrity. He comes before you saying 'forgive me for the wrongs I have committed.' Dear God, help him feel your saving grace. Restore this man to wholeness so he can come home to you soon. Amen."

Jim kept his eyes closed for a moment, tears streaming down from beyond unopened lids. Then he opened his eyes and smiled gratefully; his new sense of peace was almost palpable. It was a reminder of just how heavy guilt weighs.[9]

Soul Injury Interventions

Whereas PTSD affects a person's brain (especially the amygdala, the part of the brain that reacts to real or perceived threats), a soul injury affects a person's sense of being. Soul injury interventions, including the subcategory of moral injury, focus on learning how to mourn losses, forgive self and others, and cultivate love and compassion. These interventions are not routinely taught in healthcare or trauma curricula. However, providing these interventions at the end of life, when soul injuries tend to surface, can have a dramatic impact on a dying person's quality of life, as well as that of their family. It is essential that clinicians know how to create a safe emotional environment that allows soul injuries to surface. This includes not dismissing or minimizing guilt with well-intentioned platitudes such as: "You were following orders" or "You were being a good soldier; we have our freedom because of you." Instead, the clinician needs to create a safe emotional environment so guilt and shame can be revealed *if the veteran so chooses.* However, this needs to be done cautiously. At no time should the clinician overtly, covertly, or subtly convey that the veteran "needs to forgive," for example, saying, "You need to forgive ______ so you can have peace." This can actually add another layer of damage by causing additional guilt about the inability to forgive themselves or others. Rather, the clinician should simply offer the consideration of forgiveness and invite the veteran to stay open to its possibility. "Now is a time to look back over your life. Is there anything that might still be troubling you? Anything about the war that might still haunt you?" Then, sit quietly. These are not the kind of answers that can be hurried.

A tool has been developed to self-identify soul injuries (Box 44.2).[13]

It can be a useful tool for initiating conversations about unresolved issues that might complicate peaceful dying. This self-awareness tool should not be understood as providing any type of diagnosis or healthcare recommendations. Self-administered screening tools such as the Soul Injury Self-Awareness Inventory are designed to enhance awareness of one's own experiences for the purpose of raising awareness of feelings and experiences related to possible soul injuries. Highlighting these experiences may offer an opportunity to reflect on them at greater length or to consider their relevance in a broader life context. It provides an opportunity to consider seeking the advice of counseling professionals (such as physicians, mental health counselors, clergy, social workers, or others) who specialize in grief, loss, forgiveness, and self-compassion.

Honoring Veterans: A Portal for Healing

Honoring veterans and thanking them for their service to their country is a simple act that often precipitates the story-telling process. Bearing witness to a veteran's story can begin the healing process. There are many ways to honor veterans. Ceremonially pinning veterans with an American flag pin or presenting them with a military certificate that cites their service and displays the seal of their branch of service are simple, yet effective ways. If the veteran served in Korea or Vietnam and they express sentiments about not being welcomed home or being mistreated by the American public, it is not too late to apologize: "I am so sorry for the indignities you've had to suffer because of our nation's ignorance about war. I want you to know that you *are* a hero. And *unsung* heroes are the *most* worthy kind."

Fallen Comrade Ceremony

Ceremonies are an effective way to respond to soul injuries, even long after they occur. Native Americans have long recognized the soul injury of war and designed rituals that help warriors "decontaminate" their hostile energy before reintegrating into the tribal community.[14] The ceremony acknowledges the hardships, provides information about how to face the challenges, and integrates the experience symbolically. Well-designed ceremonies are effective because they access the *unconscious*; they access the deepest levels of the soul.

Opus Peace, an organization dedicated to tending to soul injuries, has developed ceremonies that respond to the hardships incurred by veterans and their families. The Fallen Comrade ceremony originated when Opus Peace was providing consultation services for a long-term care facility to assist staff in caring for the unique needs of aging veterans. One veteran was asked, "Is there anything from the war that might still be troubling you now?" The veteran started crying, saying, "My brother and I both went to Vietnam, but I was the only one who came back." Then, he added, "I didn't even get to go to his funeral." A memorial service was subsequently provided for him, as well as all the veterans at the facility who held similar losses. Unmourned loss and unforgiven guilt were finally liberated and the result was visibly evident.[2]

The Fallen Comrade ceremony is carefully designed to provide a safe sanctuary where losses are acknowledged, honored, mourned, and redeemed. Such losses might include the loss of comrades who

Box 44.2 Soul Injury Self-Awareness Inventory

Many people have acquired soul injuries at one time or another. The definition of soul injury is:

1. An overlooked, unassessed wound that separates one from one's "real" self, causing one to feel less than whole
2. An aching wound perpetuated by unmourned loss, unforgiven guilt/shame, and diminished self-compassion that is often manifested as a sense of emptiness, loss of meaning, or a sense that a part of self is missing
3. A long-lasting response to a person or situation that causes one to feel personally defective, inadequate, or incomplete

Circle the answer that most closely reflects your experience most of the time:

1. I am not able to be my real self.
   1 Always true 2 Often true 3 Sometimes true 4 Never true
2. I engage in some activities to help me avoid uncomfortable feelings.
   1 Always true 2 Often true 3 Sometimes true 4 Never true
3. When I avoid uncomfortable feelings, it often causes problems with people in my life.
   1 Always true 2 Often true 3 Sometimes true 4 Never true
4. I have a hard time facing loss, change, disappointments, or transitions.
   1 Always true 2 Often true 3 Sometimes true 4 Never true
5. Guilt and/or shame haunt me.
   1 Always true 2 Often true 3 Sometimes true 4 Never true
6. I feel defective, inadequate, or unworthy.
   1 Always true 2 Often true 3 Sometimes true 4 Never true
7. Self-compassion is difficult for me.
   1 Always true 2 Often true 3 Sometimes true 4 Never true
8. I struggle to find meaning in my life.
   1 Always true 2 Often true 3 Sometimes true 4 Never true
9. Have you identified a possible *soul injury?*
   Yes _____ No____ Not Sure _______
10. Do you think a past *soul injury* is affecting your life now?
    Yes _____ No____ Not Sure _______

Score of 8–16: Consider consulting a professional who specializes in loss, grief, forgiveness, and self-compassion.
Score of 17–24: Explore www.OpusPeace.org and/or www.Soul Injury.org websites for more information about the impact that soul injury might be having on your life.
Score of 25–32: You have probably worked hard to achieve and maintain a strong sense of self.

died in battle, loss of physical and mental health, or the loss of their prewar self. Family members are encouraged to attend because they are secondarily impacted by their loved one's trauma, and they are the ones providing support on a regular basis. Civilians and staff are encouraged to attend so they can learn how to provide care that supports the unique needs of veterans. Opus Peace is now training leaders to provide Fallen Comrade ceremonies throughout the nation so the wounds that veterans sustained in the public's name can be healed together.

Bereavement for Families of Veterans

Stoicism can affect whole family systems.[15] Grief might be hidden by a silent or angry facade. If the veteran was "career military," the family may have lived in numerous places for short periods of time. This can have different effects on bereavement. Because they have no established roots, there may not be a network of support that facilitates effective grieving. On the other hand, because of frequent moving, families of veterans may readily reach out for support because they have learned how to ask for help and form new bonds quickly.

PTSD does not exist in isolation; it affects whole family systems—even generations of family systems. Living with someone who is easily triggered, suspicious, and wary is difficult. If the PTSD becomes exacerbated during the dying process, the family caregivers may be exhausted and not have the energy required for grief work. They may have become so consumed with caregiving that they have lost their own life or sense of self, which makes grief recovery more difficult.

If PTSD is identified for the first time as a veteran is dying, the impact on the family needs to be factored into their bereavement needs. Some feel relieved, saying, "I'm so glad to know it has a name. I knew something was wrong but I didn't know what. Now this makes sense." Others might feel guilty. "I wish I would've realized this sooner, I would have (listened more carefully, gotten him help, been more patient and understanding, etc.)."

All of these factors need to be taken into consideration when providing bereavement care to families of veterans. They, too, have unique needs because of their loved one's military service.

Conclusion

Healthcare providers need to become sensitized to how military service influences veterans in ways that can sometimes complicate peaceful dying. Stoicism, PTSD, and soul injury are a few of the issues that healthcare professionals need to consider when intervening with veterans. Responding to the unique needs of this underserved population helps to ensure that the men and women who served our country will receive the honor they earned.

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CHAPTER 45

Organ Donation

Lissi Hansen and Lauren F. Dunn

Key Points

- The palliative care team can play a critical role in symptom management of patients who may be candidates for organ donation after circulatory death (DCD) and in support of the families of these patients.
- Early referral to an Organ Procurement Organization (OPO) gives the OPO staff time to gather information to determine whether a patient is a candidate for donation. If the patient is a potential candidate, the family will not be approached about donation options until the appropriate time.
- OPO-designated requestors are specially trained in communication and should be the ones to approach families about organ donation. Preferably, someone who has not been part of the direct care team initially presents the topic of donation to the family.
- There is no age limit to sign up on the donor registry or be evaluated as a potential donor.

Introduction

Organ donation is the process of giving an organ, organs, or a part of an organ to transplant into one or more people.[1] Most organ donations occur after the donor has died, but some organs can be donated by living donors, such as a kidney or part of the liver. In 1954, American Ronald Lee Herrick was the first living organ donor.[2] He donated a kidney to his identical twin brother, Richard J. Herrick, in what is recognized as the world's first successful organ transplant.[2,3] Receiving an organ is perceived by most as a great opportunity that is rarely needed. However, the reality is that the need for organ donations is great and the opportunity rare. The opportunity is becoming increasingly rare because of a widening gap between organs available for transplantation and the growing number of individuals waiting.[4,5] In the United States approximately 1% of all individuals die in medical settings (e.g., intensive care units), and this facilitates organ donation.[6] According to United Network for Organ Sharing (UNOS) August 2017 US data, more than 116,800 individuals were on the transplant waiting list for a life-saving organ.[7] From January 1, 2017 to July 31, 2017, a total of 20,183 transplants were performed, and the total number of donors was 9,503. In 2016, 5,891 died while waiting on the transplant waiting list and 6,392 were too sick to be transplanted.[8] Every 10 minutes, someone is added to the waiting list.[7]

Global Organ Donation and Transplantation Statistics

The Global Observatory on Donation and Transplantation (GODT) compiles a worldwide database concerning activities in organ donation and transplantation.[9] Their data collection is led by the joint World Health Organization (WHO) and the Spanish Transplant Organization, Organización Nacional de Trasplantes (ONT). There are 77 countries with donor programs. In 2014, worldwide, a total of 119,873 solid organs were transplanted, and 27,397 organs were donated from deceased individuals. GODT estimates that the number of organs transplanted is 10% or less of the need globally.[9]

US State and Federal Regulations

In the United States since 1968, federal and state legislative bodies have enacted laws to govern organ donation, including safeguarding standards for organ procurement organizations and hospitals.[10] State laws primarily cover issues related to the donation process, public education programs, and the composition of donor registries. Federal laws primarily address organ procurement, allocation, and transplantation processes.[11]

Uniform Anatomical Gift Act of 1968, 1987, and 2006

In 1968, the Uniform Anatomical Gift Act (UAGA) was drafted by the National Conference of Commissioners on Uniform State Laws. The UAGA was the first legislation enacted by all states. It establishes the Uniform Donor Card as a legal document to address donation of organs as a gift to someone who may be in need of an organ. The UAGA states that anyone over the age of 18 can legally donate his or her organs upon death.[12,13]

The 1987 version of the UAGA was developed to address significant advances in the science and practice of organ transplantation since 1968. The 1987 UAGA addresses the prohibition of the sale of human organs, the guaranteed priority of decedents' wishes with respect to the donation of their organs, the streamlining of processes for completion of necessary documents for organ donation, the mandate for hospital personnel to develop procedures of "routine inquiry/required request," and the permission for coroners to provide transplantable organs from subjects of autopsies within certain conditions.[14,15] The 2006 UAGA revised the earlier UAGAs and focused on donations from deceased donors as a result of gifts made before or after their deaths.[16] Individuals who do not have a document of gift in place may have their organs donated by people close to them based on a list of legal next of kin.[16]

National Organ Transplant Act of 1984

In 1984, Congress passed the National Organ Transplant Act (NOTA) and established the Organ Procurement and Transplantation Network (OPTN) and the Scientific Registry of Transplant Recipients. NOTA prohibits the buying and/or selling of organs. The goal of the OPTN is to ensure equitable allocation of donated organs. The contract to develop conditions for the operation of OPTN was awarded to the United Network for Organ Sharing (UNOS) in 1986. UNOS is a private, nonprofit organization. The mission of UNOS is to "advance organ availability and transplantation by uniting and supporting our communities for the benefit of patients through education, technology and policy development."[17]

The Omnibus Budget Reconciliation Act of 1986

The Omnibus Budget Reconciliation Act of 1986 requires hospitals to be affiliated with a federally mandated OPO, which is responsible for the coordination of the procurement and transplantation process.[18] The Reconciliation Act also mandates that hospitals are in compliance with UNOS and have in place policies that offer all families of patients who die the opportunity to donate their relatives' organs.[18,19]

Centers for Medicare and Medicaid Services (CMS)

In 1998, as part of the 1997 National Organ and Tissue Donation Initiative, the Health and Human Services (HHS) Health Care Financing Administration (HCFA) revised its Hospital Conditions of Participation for Organ, Tissue, and Eye Donation.[20] The HCFA is now known as Centers for Medicare and Medicaid Services (CMS). The HCFA revision maximizes opportunities to donate by requiring all Medicare-participating hospitals to (a) report all deaths or imminent deaths to the local OPO, (b) have an agreement with a tissue bank in addition to the OPO, (c) determine who makes the potential organ donation request to families and requires that person to be a designated requestor, (d) ensure that families of all potential donors are informed of their options to donate, and (e) educate staff about organ donation and working cooperatively with the OPO to medically support potential donors throughout testing and placement of organs.[10,18] Potential donors include individuals with nonsurvivable injuries in need of life-supporting medical management. For hospitals that are noncompliant with the terms listed in the Hospital Conditions of Participation in Medicare and Medicaid programs, their Medicare reimbursement may be affected.

Organ Donation Attitudes and Perceptions

People who donate their organs give others a second chance for life or an improved life (e.g., corneal transplant). The shortage of organs for transplantation is a universal problem. There are many social, cultural, and religious factors contributing to the shortage, and misconceptions and myths about organ donation persist. In general, public attitudes toward deceased organ donation are positive; however, positive attitudes have not translated into registration as a donor.[21,22] In the US 2012 National Survey of Organ Donation and Attitudes and Behavior, 94.9% of the nationally representative sample of 3,200 adults supported organ donation, but only 60.1% had granted permission for donation on their driver's license.[22] Women were significantly more likely than men to strongly support donation. Those aged 66 and older and those with an education level of high school or less were less likely to support organ donation. In the United States, African Americans and Hispanics have been found to be less likely to grant permission for organ donation than whites. African Americans are the largest minority group in need of organ transplants. In 2017, 30% of those waiting for a transplant were African Americans. In 2014, 16% of all deceased donors were African Americans.[23]

Reasons for not wanting to donate after death include a desire not to have one's organs removed, religious beliefs, and issues with trust in the fairness of the organ allocation system.[4,21,24] The main reason given for being an organ donor is a chance to help others and to save lives.[25,26] Other factors supporting organ donation by survivors are explicit knowledge of the deceased's wishes by families or that organ donation would be consistent with the deceased's personal qualities and values.[27]

Although the first priority of healthcare professionals is to save lives, some question whether professionals will try hard enough to save their lives if it is known that they are organ donors.[21] Others perceive age, illness, or physical defects to be contraindications for being an organ donor. However, everyone is a potential donor, regardless of age or health status, and can register as an organ and tissue donor. A 107-year-old Scottish woman donated her corneas after her death.[28] Teddy, a newborn with anencephaly lived for 100 minutes. After his death, his parents donated his kidneys.[29]

Clinical Trigger for Organ Donation

One of the most important roles of the bedside nurse in regards to donation is recognizing patients who should be referred to the local OPO. Each OPO establishes triggers for making a referral, which generally include the loss of one or more brainstem reflexes or discussion by family to withdraw mechanical life support. Although the specific criteria for the trigger may vary by region, the goal is for early identification of patients who may die during the current hospitalization. Many patients with neurologic injuries (e.g., anoxia, cerebrovascular accident, or trauma) meet the clinical criteria on admission, so the referral may happen very early in the hospitalization. These patients are ventilator-dependent with either (a) a Glasgow Coma Score of 5 or lower; (b) meet two of the following indicators: no response to painful stimuli, no spontaneous respirations, no corneal reflex, no pupillary response, no cough, no gag, no doll's eyes, no response to cold calorics; or (c) there is a plan to withdraw life support.[30] It is important to know that making a referral to the donation agency has no impact on the medical treatment that is being provided to the patient. This early referral simply gives the OPO staff time to gather information and determine whether the patient is a candidate for donation. Then, if the patient becomes brain dead or if the family decides to withdraw life support, the OPO staff is informed and can present the family with their options for donation.

Organ Donation and Palliative Care

Although palliative care and organ donation may seem to be two mutually exclusive paradigms, there is significant potential for synergy between them. Most patients with serious illness who are admitted to medical settings would benefit from early referral to palliative care. As a patient's medical condition deteriorates, members of the palliative care team can establish a close relationship with families by devoting time to intensive communication and assessing and addressing their needs. The palliative team can explore and establish goals of care based on patient and family values and wishes, manage complex symptoms, and coordinate care among the patient's various healthcare teams. For patients who are not brain dead but may be candidates for organ donation after circulatory death (DCD), the palliative care team can continue to play a critical role in managing their symptoms (e.g., pain, air hunger). Working with these patients and their families, members of the palliative care team may receive information about organ donation wishes. Such wishes may be expressed by family members during their communication about the patient and should be shared with OPO staff.

Referral Process

The referral process is designed so that hospital staff members do not have to be trained in the variable rule-out criteria for the three types of donation: organ, tissue, and eye. Rather, this determination can be left to the donation professional; hospital staff simply need to contact them. Referring a patient to the local OPO can be done by any hospital staff member, including the physician, nurse administrator, or chaplain, but is generally the responsibility of the bedside or charge nurse. The Health Insurance Portability and Accountability Act (HIPAA) includes an exemption for hospital staff to release patient information to the OPO without obtaining consent to do so from the patient or family.[18] In fact, hospitals must provide this information to be compliant with the CMS Hospital Conditions of Participation.

During the initial call to the donor referral line, a triage operator will take general patient information including name, date of birth, admission diagnoses, and mechanical ventilation status. An Organ Donation Coordinator will receive the referral if the patient is on mechanical ventilation. If the patient is not on a ventilator, they will be evaluated for eye and tissue donation only.

When the Organ Donation Coordinator receives the referral, the nurse will then be asked to provide additional information about the patient, including the hospital course of events, past medical history, current laboratory values, and sometimes diagnostic testing results. If the patient does not have any automatic exclusions for donation, the coordinator will review the full medical record, either remotely or onsite. The coordinator may also gather more information from hospital staff regarding the patient's plan of care and family dynamics. If the patient is considered a potential organ donor candidate, the OPO will followup with the hospital for daily updates. The family will *not* be approached about their donation options until the appropriate time. Many patients who are referred improve neurologically, at which time the OPO coordinator will sign off and stop following the patient as a potential donor.

Donation Discussion with Family

The optimal time to speak with a family about donation is generally thought to be after they have accepted that their relative is not going to survive. If a family is still hopeful for their loved one's recovery, it is not an appropriate time for them to be approached about donating organs.[31] Acceptance of impending death can be demonstrated in many ways. The family may begin discussing the withdrawal of life support, the patient has formal brain death testing performed and the family understands this diagnosis, or, in some cases, the family asks about the possibility of donation. The hospital staff is vital in keeping the donation team updated about the patient's clinical status and any end-of-life (EOL) discussions with the family. The OPO has designated requestors who are specially trained in speaking with families about donation. Some hospitals have in-house staff who are trained by the local OPO as designated requestors as well. It is preferred that the topic of donation is initially presented to the family by someone who has not been part of the direct care team. This decoupling between the medical team and the donation team prevents false perceptions that the care team has any motive in the treatment of the patient other than saving the patient's life.[32] The designated requestor will also have important information about whether the patient is registered as a donor through the Department of Motor Vehicles (DMV) or online registry.

If a family asks about donation, the nurse can offer to contact the donation agency and have a requestor speak with them about their options and answer any questions. For example, the nurse could say something like "we can definitely see if donation is an option; let me contact the donation representative." If it is early in the hospitalization, it might feel more appropriate to say something like "right now we are doing everything we can for (loved one), but we work closely with the donation agency and they will inform you of your donation options if we get to that point." The nurse should contact the OPO to update them that the family has asked about donation. The requestor may also be able to provide language for the nurse to use that is appropriate for the specific situation. In addition to keeping the OPO informed, bedside nurses serve as familiar, trusted caregivers to the family. When it is time for the donation discussion, the information that the nurse has provided to the OPO helps set the stage for a successful conversation. The goal of the conversation is for the family to feel supported and to be given accurate information so they can make the best decision for their loved one.

Donor Designation

When an individual has registered to be an anatomical donor through the DMV or online registry, it is considered first-person authorization. This is similar to an individual having an advance directive for medical treatment. The donation discussion with the family is very similar to when a patient is not registered, but, instead of having to make a decision about donation, the family is informed about the process of honoring the patient's directive. The designated requestor is trained to work through concerns with the family in the event that they are not in agreement with the registry status. When a patient has expressed his or her intent to donate by signing up on the donor registry, the OPO makes every attempt to honor that decision.

Family Concerns

As public education organizations such as Donate Life America work to increase public awareness about donation, registry rates across the country are increasing.[33] Even with increased knowledge, myths about the donation process continue to persist. Designated requestors are trained to address family concerns or questions about the process. It is important to always have an OPO representative involved when family members have questions to ensure that they are given the most accurate information.

Timing

Many families expect donation to progress as it is seen on television, where the family signs the consent and the patient is immediately taken to the operating room (OR). In reality, the process takes time, and sometimes this is concerning to families. The OPO representative will explain that the time is needed to perform tests and to identify the best possible recipients for the organs. The OPO will always work with the family to attempt to meet any timing needs.

Cost

No additional expense will be incurred by the family if their loved one is a donor. All of the hospital costs associated with the donation process are covered by the donation agency. The family remains responsible for pre-donation hospital expenses (the portion of the hospital bill prior to authorization for donation), funeral expenses, and the cost associated with cremation/burial arrangements. The family will not receive any monetary compensation for the donation, as prohibited by federal law.

Pain/Discomfort

If family members express concern that their loved one is in pain or that the process is prolonging their suffering, there are a number of ways to address this. If the patient has been formally declared brain dead, families can be assured that this is the legal time of death, and their loved one is no longer feeling any pain. If a patient is not brain dead, the hospital staff will be called upon to discuss their plan regarding comfort care medications and EOL symptom management (e.g., secretions, pain). If the palliative care team is not already involved in the patient's care, a consult should be made at this time.

Allocation

For potential recipients to be listed to receive an organ, they have to go through an extensive screening process and be approved by a transplant center. The federally regulated, nonprofit organization UNOS maintains information on all listed patients and generates organ-specific lists for each donor. Potential recipients on the lists are prioritized by factors such as total wait time, medical urgency, blood type, and geographic location.[34] Wealth or fame cannot get a patient moved up on the list.[35]

Religion

All major religions either support organ donation or support the individual's right to choose.[36] Families are encouraged to consult with their faith leader if they have questions.

Paths to Deceased Organ Donation

There are two ways to be legally declared dead in the United States: by neurological criteria (brain death) or by cardiopulmonary arrest (circulatory death). Donation proceeds differently depending on the type of death.

Brain Dead Donation

The Uniform Determination of Death Act defines brain death as the "irreversible cessation of all functions of the entire brain, including the brain stem." The three clinical findings that are necessary to confirm brain death include unresponsiveness (coma) due to a known cause, absence of brainstem reflexes, and apnea (complete absence of respiratory effort).[37] Formal testing has to be performed by a physician for a patient to be legally declared brain dead. Brain death testing varies by state and by hospital policy on details such as the type of physician who may perform the testing, whether it should be repeated by a second physician, and any requirement for ancillary testing, so it is important to be familiar with the policy of the hospital in which testing is being performed.

If a patient is not displaying any brainstem reflexes, it is imperative that the hospital staff perform this testing. It is important to note that brain death testing is not performed for the purposes of organ donation. It is a clinically indicated, diagnostic test that provides the care team and family with definitive prognostic information. Having the diagnosis of brain death also eliminates the emotional burden on the family of having to decide if and when to withdraw life support.

After a patient has been declared brain dead and authorization for donation has been given, the OPO staff take over medical management of the patient. The bedside nurse continues to provide care and works closely with the donor team staff to fulfill patient care orders. Because the goal of care is no longer to preserve brain function, the priority shifts to optimizing organ function. It is important for all potential organ donors to remain hemodynamically stable for perfusion and oxygenation of the organs. The Organ Donation Coordinator will educate the nurse about treatment goals and provide parameters on vital signs and urine output. Hypotension, hypothermia, electrolyte imbalances, and diabetes insipidus are common in brain-dead patients, and the coordinator will watch for and treat these conditions. Blood is drawn for infectious disease testing, and labs sent to begin the evaluation of organ function. The goal of the coordinator is to optimize the gift being given, so every organ without automatic exclusions will be evaluated. The brain dead patient can potentially donate heart, lungs, liver, kidneys, pancreas, and intestine. Diagnostic imaging and procedures that may be performed include an echocardiogram, coronary angiogram, electrocardiogram (EKG), bronchoscopy, chest x-ray, chest or abdominal computerized tomography (CT) scans, and abdominal ultrasound. Hospital staff will be consulted to perform these tests and to place arterial or central intravenous lines as needed.

As organs are evaluated, a list of potential recipients for each organ is generated through UNOS. UNOS uses an algorithm of many factors to rank patients on the organ-specific lists. The algorithm is designed so that the recipients are organized by best match with the highest medical urgency or total wait time. These standards are designed so that the distribution of organs is fair and ethical while attempting to minimize the number of patients who die while waiting for an organ.[32] The Organ Donation Coordinator moves systematically down the generated list, directly contacting the transplant centers where recipients are listed. The transplant center will evaluate the donor information to make the final determination about whether the organ is a suitable match for its patient. Once a recipient for each transplantable organ is identified, the coordinator will schedule a time for the organ procurement operation. The family is kept informed about the donation process as it progresses. However, identifying information about potential recipients is kept confidential. Some families choose to stay at the bedside until the patient is ready to be taken to the OR; others say their final goodbyes after brain death is declared. The organ donation team, unit staff, and palliative care team are there to offer ongoing support to the family during this time.

Donation After Circulatory Death

A patient who is not brain dead, but who is not expected to survive after being taken off mechanical ventilation, could be a candidate for DCD. In this type of donation, the surgical recovery of organs occurs after a patient is taken off life support, allowed to expire naturally, and declared dead by cardiopulmonary arrest. These patients include those with severe neurological injuries but with some preserved neurological function, or with a condition in which they will not be able to continue breathing effectively on their own, such as amyotrophic lateral sclerosis (ALS) or a spinal cord injury. The family will only be presented with the option of DCD once they have decided to withdraw mechanical life support. This way, the decision to pursue organ donation is not a factor in a family deciding to stop aggressive life support measures.

When discussing DCD, families are informed that the withdrawal of life support will happen in a controlled setting, and their relative will remain under the care of the hospital team and receive the same EOL treatment as in a typical withdrawal of support. The hospital staff continues to provide medical management of the patient while the donation team evaluates organs and identifies recipients. Because the patient is not legally dead at this point, the organ donation team plays no part in the patient's medical care. If the hospital has a palliative care team, they will frequently be consulted to provide comfort care management during the donation process and withdrawal of life support. After donation details are in place (organs evaluated, recipients identified, OR ready, and procurement surgeon on standby), the medical staff will remove the patient from ventilator support. If they choose, the family can remain with their loved one during the dying process. The bedside nurse, respiratory therapist, and physician will be present to remove the ventilator, provide comfort care medications as needed, and pronounce the patient deceased after the heart stops. If the patient dies in the time frame needed for organ donation to occur, typically 1–2 hours, the patient will then proceed quickly to the organ procurement operation. If the patient continues to have a pulse longer than 2 hours, the organs will have suffered from hypoperfusion and hypoxia and will no longer be transplantable. At that point, organ donation efforts will cease and the patient will continue on comfort care. After cardiac death, tissue and eye donation are still a possibility. During the initial discussion of DCD, families are made aware that there is no way of definitively knowing how long their relative will live after the withdrawal of life support and that donation is not guaranteed.

If a patient expires within the required time frame, the procurement surgery has to occur quickly as the organs are no longer being perfused by oxygenated blood. A waiting period of 5 minutes has to occur after the heart stops beating to watch for any signs of autoresuscitation before the surgery will begin. The family will say their final goodbyes and the patient will be transported to the OR (if the withdrawal of support did not occur there) and prepped for surgery during this time. The organs suffer a period of ischemia during this type of donation, so, in general, a candidate for DCD has slightly tighter criteria in terms of age and health to qualify. Also, because of this period of ischemia, heart and intestine are not usable from DCD donors, but the deceased can still potentially donate liver, kidneys, pancreas, and lungs.

Operating Room: Organ Procurement Surgery

The organ recovery surgery is a complex procedure that takes the expertise of surgeons specially trained in procurement and the assistance of the hospital OR staff. Typically, one local surgical procurement team will recover the abdominal organs with separate surgical teams from the accepting heart and lung transplant centers. The OPO staff will help with logistics of the surgery including coordination and communication among teams, organ packaging, and transportation. Before the surgery begins, a team pause is observed in which the donor will be honored for the gift that he or she giving. Some families choose to prepare a brief statement about their loved one, which is read during the pause.

With a brain dead donor, the surgery will begin with the patient still on the ventilator and the heart beating. A single midline incision is made to access the abdominal and thoracic cavities. The organs and vasculature are isolated and a visual inspection of the organs is performed. The surgical teams place cannulas in the major blood vessels that supply each organ. Simultaneously, a clamp is placed on the aorta and preservation solution is started to flush the organs. The cold preservation solution stops the heart and begins to cool the organs. The warm blood is vented out through an incision in the vena cava and suctioned from the abdominal and thoracic cavities. Sterile ice is packed into the body cavity to cool the organs while they are individually removed.

As the organs are being recovered and teams are traveling back to the transplant centers, recipients are being prepared for their transplant surgery. Much coordination goes into minimizing the time frame between organ removal and transplant into the recipient. The less time the organ spends on ice, the better it will function after being transplanted. See Figure 45.1.

Aftercare Services

OPOs have donor family aftercare specialists who provide ongoing support for families in the months and years after their relative's death. After the donation process is complete, the donor family will receive a letter with nonidentifying information about the recipients whose lives were saved by the gift of an organ. Any correspondence between recipients and donor families is facilitated by the aftercare specialist unless both parties agree to release their information. Aftercare programs also hold events in honor of donors, in which families can choose to participate. Many families find the donation community to be a source of comfort and support during their time of grief.

Case Study: An Organ Donation

Mr. James Peterson is a 72-year-old man who was admitted to the trauma intensive care unit (ICU) from the OR. He was the driver in a head-on collision with his wife Maria in the passenger seat. Mr. Peterson was intubated in the field and provided ventilatory support. Mrs. Peterson suffered only minor injuries. She was treated in the emergency department (ED) and then released.

Mr. Peterson suffered a severe closed-head injury. A computed tomography (CT) scan of his head revealed a large subdural hematoma with right-to-left shift. He was taken to the OR for a craniotomy. After surgery, Mr. Peterson was medically treated including hyperventilation to reduce cerebral edema. Forty-eight hours after

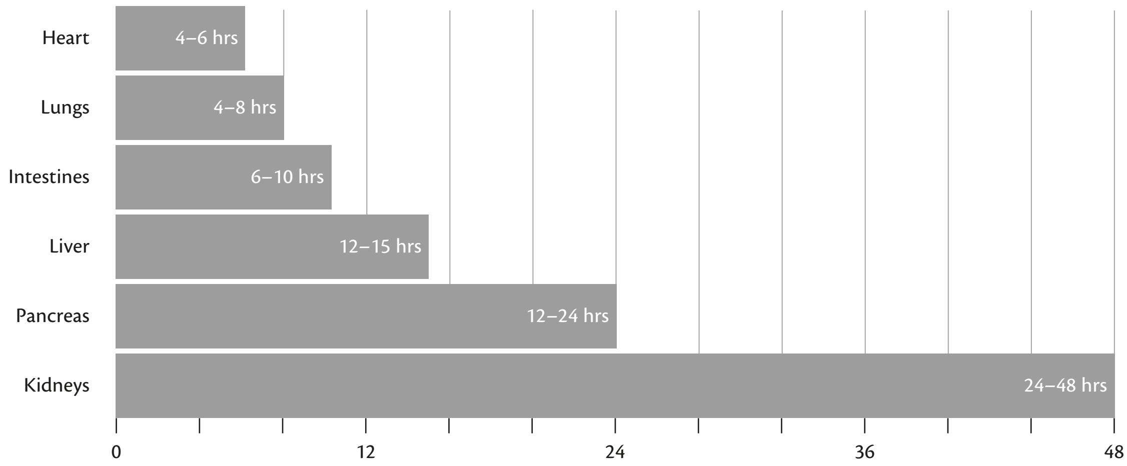

Figure 45.1. Organ preservation times.
Source: Megan MacNee, Program Manager, Donate Life California. http://donatelifecalifornia.org/wp-content/uploads/2013/01/organ-preservation-times-pic.jpg

surgery, he showed no sign of improvement. His body posture decerebrated to noxious stimuli and his pupils were unequal and with sluggish reaction to bright light. The neurosurgeon spoke to Mrs. Peterson and her two daughters about Mr. Peterson's condition and grim prognosis. The neurosurgeon made a referral to the palliative care team with a request for the team to speak with Mr. Peterson's family about goals of care. The family wanted everything done for Mr. Peterson. They could not imagine a life without him.

The following day Mr. Peterson experienced a sudden episode of hypertension and irregular heart rate followed by hypotension. The staff acted quickly to normalize his blood pressure by giving a fluid bolus and starting dopamine. Findings of Mr. Peterson's neurological examination had changed. He had a Glasgow Coma Scale score of 3, fixed and dilated pupils, no gag and cough reflex, and no spontaneous respirations or purposeful movements to noxious stimuli. After the consulting neurologist had completed her brain death testing and evaluation of a cerebral blood flow (CBF) study, Mr. Peterson was pronounced brain dead.

The intensive care nurse who had taken care of him for the past 2 days contacted the Donor Referral Line. The nurse regretted that she did not speak with the OPO earlier, as Mr. Peterson met the clinical trigger for referral 3 days earlier. She had recently learned that there was no age limit to signing up on the donor registry or to be evaluated to donate. An earlier referral of Mr. Peterson to the OPO would have facilitated information gathering about him by the OPO. This medical evaluation can take several hours and would have been completed prior to the herniation event.

The nurse from the palliative care team was visiting with Mrs. Peterson and her daughters when the neurosurgeon informed them about the death of Mr. Peterson. The family was understandably very upset upon hearing that Mr. Peterson had died because they had held out hope that he could pull through.

The Organ Donation Coordinator arrived onsite and had to quickly review Mr. Peterson's medical record to see if there were any donation options to offer the family. Luckily, the family had asked his bedside nurse for more time to gather additional friends and family members to say goodbye. The coordinator found that Mr. Peterson was previously very healthy and active, and his current labs values were normal. The coordinator also checked the donor registry and found that he had not signed up to be a donor. The coordinator talked with the bedside nurse, palliative care nurse, and the neurologist to learn about the family and where they were in their understanding. The neurologist stated that, despite their initial shock, the family was fully understanding of the brain death diagnosis. The bedside nurse mentioned that the family had asked what happened after they all said their goodbyes. Everyone was in agreement that now was a good time to present them with information about donation.

The palliative care nurse, who now had a relationship with the family, asked Mrs. Peterson and her daughters if they would come to the conference room to discuss some additional decisions. They met with the donation coordinator and were surprised to learn that Mr. Peterson had the potential to be a donor. They shared that Mr. Peterson worked as a teacher and was always volunteering in the community. They knew that he would have wanted to help others in any way he could. They went through the paperwork with the coordinator and decided that they wanted to say their final goodbyes and leave the hospital. The coordinator agreed to keep them updated about the process.

Ultimately, Mr. Peterson was able to donate his liver and both kidneys to three fortunate recipients. He was also able to donate his corneas, skin, bone, and vascular tissue of the heart, which would improve the lives of countless recipients nationwide.

Six months later, the Peterson family received a letter from one of the kidney recipients. She was a 65-year-old retired nurse who thanked them for their decision to donate. She no longer required dialysis and was so grateful to spend more time with her grandchildren. The Peterson were so proud that Mr. Peterson's final act was one that helped so many.

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CHAPTER 46

Pulmonary Palliative Care

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Key Points

- The American Thoracic Society (ATS) has issued a Clinical Policy Statement on Palliative Care for Patients with Respiratory Diseases and Critical Illness.
- There are available triggers to use to identify patients in need of referral to a pulmonary-palliative medicine clinic.
- Regardless of prognosis, much can be done to optimize management of the advanced pulmonary patient.
- This chapter provides an overview for the rationale and justification of early integration of palliative care for the advancing/chronic lung disease patient.

Introduction

Patients with advanced/terminal lung disease require a more comprehensive approach to assure relief from suffering and distress as well as reassurance that they will be cared for through the trajectory of their chronic, progressive illness.[1] Additionally, family/caregiver support is also a priority. Patients with advanced lung disease have physical, psychological, social, and spiritual issues that reduce their quality of life (QOL). The emotional dimensions of chronic conditions are often overlooked when medical care is considered, and, while it may be difficult to diagnose depression in the medically ill, diagnosis and treatment are essential.[2,3] Data show 18% of US gross domestic product is spent on healthcare, with $3 trillion spent on healthcare annually in the US (twice the amount spent on food) and 33% spent on hospitalization costs. By 2037, the percentage of gross domestic product is expected to increase to 25% and this spending is unsustainable.[4] Furthermore, despite these high expenditures, health outcomes in the US are not considerably better than in other high-income countries.[4]

Today's healthcare providers are well-equipped for the biomedical aspects of care but not for the challenges of understanding the psychological, social, and cultural dimensions of illness and health. Clinicians on every level can play an important part in helping their patients to develop and maintain healthy coping skills.[5]

Of all the advanced lung diseases, chronic obstructive pulmonary disease (COPD) is the leading diagnosis for respiratory failure–related deaths[6]:

- The Global Burden of Disease Study reports a prevalence of 251 million cases of COPD globally in 2016.
- An estimated 3.17 million deaths were caused by the disease in 2015 (this is 5% of all deaths globally).
- More than 90% of COPD deaths occur in low- and middle-income countries.

On average, more people die every day from COPD than from diabetes or breast cancer: 377 per day from COPD versus 193 per day from diabetes or 112 per day from breast cancer.[6,7]

Most people nearing the end of life are not physically, mentally, or cognitively able to make their own decisions about care. Of people who indicate their end-of-life (EOL) care preferences, most choose care focused on alleviating pain and suffering.[5] Frequent clinician–patient conversations about EOL care values, goals, and preferences are necessary to avoid unwanted treatment. Incentives, quality standards, and system support are needed to promote improved communication skills and more frequent conversations.

Recommendations from the American Thoracic Society,[8] Institute of Medicine (IOM),[2,3] National Consensus Project (NCP) Clinical Guidelines,[9] and the American Society of Clinical Oncology[10] (ASCO) provide support for the framework of this comprehensive care plan. Much of the data stem from cancer-based research. However, the 2013 NCP report analyzed patients of any age with multiple comorbid/chronic conditions, with the intent to offer the focus of palliative care interventions for the most seriously ill. The NCP integrates central quality assessment and improvement initiatives into palliative care, and it describes the comprehensive care necessary for patients at the end of life. These clinical guidelines emphasize the patient- and family-centered focus of palliative care, promoting access to palliative care across all patient populations and all health settings. In addition, there is expansion of the composition and necessary education of the intradisciplinary team beyond chaplaincy, medicine, nursing, pharmacy, and social work to include rehabilitation therapists, respiratory care, and other therapies.[8–10]

The American Thoracic Society (ATS) issued a Clinical Policy Statement: Palliative Care for Patients with Respiratory Diseases and Critical Illnesses, which delineates the obligations of pulmonary providers to the patients we serve. The ATS acknowledges that pulmonary providers routinely care for patients with chronic or advanced respiratory diseases and critical illnesses.[8] The ATS recognizes the growing importance and complexity of palliative care for patients with life-threatening and life-limiting diseases and disorders and the need for improving professional competence and teamwork in providing such care. The statement strongly endorses the concept that palliative care should be available to patients at all stages of illness and should be individualized based on the needs and preferences of the patient and the patient's family. Finally, the ATS believes that clinicians should consult with palliative care specialists as appropriate for managing palliative care situations beyond the clinician's level of competence.[8]

Dyspnea: Why Is It Important?

Before reading this next section, please see the Dyspnea Empathy Exercise in Box 46.1 developed by Dr. Betty Ferrell. Dying patients fear dyspnea and pain; therefore, symptom control is one cornerstone of pulmonary palliative care. Dyspnea is a prominent symptom of the patient with advanced respiratory disease of any cause: Nearly all patients with COPD had dyspnea during the last 3 days of their lives.[11,12] Since the publication of the original ATS consensus statement in 1999, there has been substantial progress made in research into mechanisms of dyspnea. However, there has been little progress in treatment of dyspnea.[13] Despite advances in the therapy of several cardiopulmonary disorders, there are millions of patients who are severely disabled by breathlessness. Efforts to cure disease are the focus of much biomedical research and tend to grab the public's attention. However, the duty to alleviate suffering must remain a top priority. The ATS concludes: "It is our hope that this document summarizes the progress that has been made and what remains to be done to allow our patients to enjoy one of our most primal needs—breathing."[13]

Pulmonary-Palliative Clinic: A New Construct

Although those with advanced lung disease may receive "palliative" or life-prolonging treatment, this usually does not address their physical, psychological, social, or spiritual issues—and may worsen them. In our work at Geisinger Medical Center, we hoped to establish a dedicated clinic with the time and staff educated to address these issues in a safe forum for our patients and their families, a place that would allow a continued dialogue with patients and their families. The reality is that earlier involvement of palliative care leads to improved QOL for patients and families, as well as a more efficient utilization of medical resources in a more appropriate, even cost-saving, manner[14,15] and higher patient satisfaction when the "unknown" is no longer a dark, scary mystery. The intention of the Pulmonary-Palliative Medicine clinic is to encourage these discussions earlier in the trajectory of chronic, progressive illness. In keeping with the tenets of palliative care, the earlier referral and integration of palliative care services into the management of advanced disease led ultimately to improved QOL and higher patient and family satisfaction.[16] Practice is carried out with the realization that there are different levels of training among providers of palliative care:

Box 46.1 Dyspnea Empathy Exercise

While seated, take a normal resting breath but only exhale partially.

Wait a few seconds and take another resting breath and only exhale partially.

Wait a few seconds and repeat.

After a few more seconds, breathe normally.

After this simple exercise, ask yourself these questions;

What was your experience? How did you feel? Were you a little anxious? Did you feel some stress? Was it unpleasant?

This exercise causes a 4–5 mm Hg elevation in CO_2 from your baseline, with an associated dyspnea and affective (fear/anxiety) response. While this is a temporary, controlled exercise that can be stopped at any time, it does effectively reflect minor dyspnea. Now take a moment to imagine if this feeling was dramatically amplified, as it is with advanced lung disease patients who have no recourse or relief from the severity of their lung disease.

Source: American Association of Colleges of Nursing and City of Hope. (2017). Dyspnea empathy exercise. In: *ELNEC-Critical Care Curriculum,* Module 3 – Symptom Management, Supplemental Teaching Materials section. Duarte, CA: Authors.

Specialist: Professionals with advanced palliative care training/certification who specialize in providing symptom management and support to those with serious medical illness in parallel with their treatment as well as at end of life. The Palliative Care Specialist is adept at managing complex and refractory symptoms that may occur with disease progression as well as being an experienced navigator of the psychosocial challenges and family dynamics which accompany these circumstances.

Generalist: Professionals from other specialties with training in basic palliative care concepts/content who identify the need for and initiate advance care planning, symptom management, and QOL support for their patients. Ideally all providers should be familiar with providing basic palliative care and then refer to and collaborate with palliative specialists as needed.

The goal is to improve education and outreach to be able to arrive at an equipoise where all professionals provide basic palliative care to most patients but will refer to palliative care specialists when higher intensity/higher levels of palliative care are required to optimize patient care.[17]

Palliative Care for People with Advanced Lung Disease

Palliative care encourages and supports family involvement in planning and providing care to the extent desired by the patient. This is because chronic or advanced respiratory diseases and critical illnesses impact both patients and their families. All patients with symptomatic or life-threatening diseases, particularly those with chronic or advanced respiratory diseases or critical illnesses, regardless of age or social circumstances, should have access to palliative care. Perhaps more importantly, healthcare providers should have an appropriate level of competence in palliative care, where training and educational experiences equip the pulmonary provider with the core competencies necessary to provide compassionate and individualized palliative care.[18,19] The ATS supports efforts of public education about the availability and value of incorporating palliative care in the care of patients with chronic or advanced respiratory diseases or critical illnesses, including advocacy for research and professional education to improve the quality and availability of palliative care services.[8]

Advanced Lung Disease and Unique Circumstances

Historically, palliative care has focused on patients with malignancy. Recently, considering the mortality and morbidity of COPD as delineated earlier, there is increasing recognition of the need for similar services for individuals with respiratory conditions. This includes other nonmalignant end-stage pulmonary diseases such as cystic fibrosis, interstitial lung disease (ILD), pulmonary arterial hypertension, sarcoidosis, and occupational lung disease. Often, these conditions are treated without a concomitant palliative component until there is a sudden change in the trajectory of the illness or a decline, necessitating a sort of crisis approach to their needs.[20,21] Symptom management should address air hunger, exertional dyspnea, chest tightness, anxiety/panic, increased work of breathing as evidenced by increased accessory muscle use, increased oxygen needs, spiritual or existential distress, and grief.

Uncertainty in Prognosis and Disease Trajectory

Time from onset of symptoms to diagnosis may be delayed. With ILD, this delay has been noted to be 3 years or more, with patients seeing three providers or more before receiving a definitive diagnosis. This impacts their trajectory, delaying advanced therapies developed to slow disease progression.[22]

The disease trajectories of nonmalignant chronic lung diseases, such as COPD, ILD, pulmonary hypertension, and cystic fibrosis, are variable and characterized by considerable uncertainty. With COPD and pulmonary fibrosis, patients typically have a gradual decline, but the trajectory can change abruptly due to exacerbation of the underlying lung disease or an event caused by a comorbid condition. With this exacerbation, patients may not be able to return to their previous level of functioning.[21–23]

The disease trajectories for lung diseases such as pulmonary hypertension or lung transplant recipients differ depending on the cause of the disease, comorbid conditions, complications related to therapy, response to treatment, or surgery. These are changing with the advent of newer therapies and experienced centers for treatment.[24]

Advanced therapies to slow the progression of illness present special challenges at end of life. Patients may not understand that these are not curative. These therapies are expensive, and, with current regulations, the patient must often choose between continuing therapy and hospice.

Idiopathic pulmonary fibrosis (IPF) is a progressive disease with median survival of 2 to 7 years. IPF now has therapies available which do not reverse damage but have been shown to slow the decline in the loss of lung function as measured by forced vital capacity (FVC) on the pulmonary function test. Further drugs or drug combinations can be expected in the future. These medications may cause side effects which impact QOL. This leaves patients trading-off coping with drug-related symptoms for a hopefully longer life span.

Early Integration of Palliative Care in Advanced Pulmonary Disease

Despite recommendations for early integration of palliative care, few studies are available on end-of-life recommendations for this population. Patients may continue to have a significant symptom burden, most commonly dyspnea and cough. Their oxygen need increases over time. According to a recent study, IPF has a major impact on daily living and family relationships.[24] This slowing rather than reversal or stopping of progression may be difficult for patients and families to understand. It is important when initiating these therapies that their efficacy be clearly explained and that this information be reviewed periodically. Early referral to a lung transplant center, if applicable and if the patient agrees, is recommended.

More than 100 types of ILDs have been identified, and, for most of these patients, lung transplant is not an option.[22] Therapy varies depending on etiology, and, for some, no therapy is available. Most of these patients die in a hospital setting with ongoing life-prolonging procedures until death. Often EOL decisions are still made very late. Early integrated palliative care with advance care planning could improve their EOL care. Further studies on the care received and ways to improve end of life for this population are needed.[22,25]

Providers should begin conversations early in their care concerning when to expect to stop or reduce therapy. This should include integrating advance directive decisions. Patients and families may find it difficult to stop therapy even in the face of a decline in functional status. In the face of irreversible functional decline, the focus should be to continue treating comorbidities and be directed toward aggressive symptom management. Pulmonary rehabilitation can be considered to attempt to improve functional status and QOL.[21]

Medication Dilemmas

Pulmonary hypertension medications have their own special challenges because their efficacy often is limited and continual use may contribute to functional decline. Many of them are titrated or combined to maximize efficacy and carry the risk of rebound if abruptly stopped.[24] Patients also note improvement when they are started, so they may be reluctant to reduce or stop them for fear of becoming symptomatic. However, as the disease progresses beyond the ability of medications to control it or the patient experiences a functional decline or a dying process for another reason, this may become necessary. As with other end-of-life planning, the patient and family should be consulted on the timing of tapering medications down. The plan should include aggressive measures to manage dyspnea, hypertension, edema, or related symptoms. With oral medications, it may consist of reducing the number of tablets or frequency stepwise over time. With intravenous infusions, a gradual stepping down of rate of infusion may take days to a week or more to mediate symptoms. If possible, consider tapering off inhaled or intravenous therapy but continue PD5 inhibitors or another oral pulmonary hypertension medication. Diuretics should be continued as possible and as tolerated for management of edema and breathlessness.[24] These medications have been the patient's lifeline, many times for years, so patients may approach the process of tapering or stopping them with fear and with questions about hastening their demise despite indications of loss of clinical efficacy and functional decline.

Advanced Ventilatory Technology

Noninvasive ventilation (NIV), bimodal positive airway pressure (BiPAP) therapy, and nocturnal ventilation via tracheotomy are becoming increasingly common therapies. In the latter stages of disease and at end of life, home NIV may provide symptom relief and rest periods to offset the increased work of breathing.[25,26] In an acute situation, it may provide time for decision-making or family interaction. Patients and providers may elect noninvasive support to treat a possibly reversible comorbidity such as infection. It should be combined with aggressive management of dyspnea for patient comfort but also to facilitate the patient's ability to remove the device for communication with family and pleasure feeds. Both opioids and anxiolytics should be considered.[27] Like other advanced therapies, an early conversation about this being a temporizing therapy and when to discontinue it should occur before initiating therapy. Patients and families should be encouraged to participate in this decision as it may involve waiting for a distant member to arrive or meeting or avoiding a special date or milestone.[26]

Forecasting

Identifying which individual with an advanced pulmonary diseases will have a rapid versus more indolent progression of their illness remains the challenge. Efforts are underway to broaden our understanding. Diffusion capacity for carbon monoxide (DLCO) is a measure done as part of a full pulmonary function test; it measures the transfer of gas from air in the lung to the red blood cells in lung blood vessels. A DLCO of less than 40% predicted, desaturation with exercise, and concomitant pulmonary hypertension are poor prognostic signs. The prognosis of combined pulmonary fibrosis and emphysema (CPFE) is worse than either disease alone. For ILDs, worsening fibrotic changes on radiology, decline in diffusion capacity, increasing oxygen need and dyspnea, decline in distance on 6-minute walk test, and decline in FVC are longitudinal indicators. Unintentional weight loss, repeated hospital admissions, and progressive decline in functional status are general clinical indicators.[25]

With pulmonary arterial hypertension, accepted guidelines use N-terminal pro b-type natriuretic peptide (NT proBNP) and renal function as markers of disease severity. Other inflammatory markers such as interleukin 6 (IL-6), growth differentiation factor 15, and red cell distribution width are useful but not commonly available. Research is under way to find other markers, for example a nine-protein panel that will provide information on prognosis and response or lack of response to therapy. These could be beneficial in guiding therapy as well as in decision-making.[28]

Toll of Serious Illness on Patients and Families/Caregivers

Like many patients with advanced illness, those with advanced lung disease fear they will be a physical and financial burden.[29,30] Studies have demonstrated that caregivers of patients with advanced lung disease report needing/desiring support with physical care and education/information about advanced illness and end-of-life processes, as well as the all too important but all too often underacknowledged need for emotional and spiritual support.[30] Patients and family often worry about if "nothing more can be done," will healthcare providers abandon them? They are often consumed with worries about how their families and caregivers adjust to role changes: many drain life savings or go bankrupt to cover medical costs.[29] Approximately 40% of all COPD patients are affected by severe depressive symptoms or clinical depression, with the prevalence of depression as high as 57%, and this can often be a challenge to diagnose because of overlapping symptoms between COPD and depression.[6,8,12,29,30] As a result, advanced lung disease patients often feel helplessness or powerlessness due to their loss of mobility and freedom and their growing weakness; they report tense relationships with friends and family, often developing panic attacks with episodes of uncontrolled dyspnea and increasing social isolation as they interact less and less with their world. This can often lead to more depression, anxiety, insomnia, or sleep disturbance.[6,12,27,30]

As the Medicare data confirm, many older adults may be cared for by an aging/also chronically ill spouse; additionally, older children caring for a parent may also have acute or chronic illnesses.[31] Strategies for coping with advanced lung disease include regular exercise (which can often be "jump-started" by enrollment in pulmonary rehabilitation for qualified patients); cognitive behavioral therapy; support groups, such as the Better Breathers Club; keeping oneself emotionally open to those seeking to assist and care for them; and the positive reinforcement felt by engaging in activities which promote happiness such as time with friends and family, hobbies that bring personal joy, or meditation.[32]

The Pulmonary-Palliative Medicine Clinic at Geisinger Medical Center

At Geisinger Medical Center, a level 1 shock-trauma academic medical center located in rural north-central Pennsylvania, a shared modality clinic was initiated and developed by Nurse Practitioners with the goal of providing advanced lung disease patients with palliative and pulmonary care. This clinic allows patients and their families the opportunity to integrate ongoing management of lung disease with advanced illness planning and symptom management. Preliminary research found no previous existence of such a clinic; therefore, the need to build this from inception using evidence-based medicine became the necessity. The Geisinger Medical Center's Pulmonary-Palliative medicine is a dedicated clinic with the time and trained staff to address the multifaceted issues of advancing lung disease in a safe forum for patients and their families to pursue discussions that are an ongoing dialogue across the continuum of clinical care.

This enterprise began in 2008, with the Geisinger Medical Center's Divisions of Pulmonary and Palliative Medicine. This clinic was started by Patricia Maani-Fogelman DNP with the leadership support of respective division directors, Drs. Paul Simonelli (Pulmonary-Critical Care) and Neil Ellison (Palliative). In this setting, patients with advanced lung disease are seen by Pulmonary-Palliative Care Nurse Practitioners (the authors of this chapter) with extensive pulmonary, critical care, and palliative care backgrounds. Specific attention is given to the management of advanced lung disease symptoms, especially dyspnea, anxiety, depression, and fatigue, as well as to initiating discussions to establish goals of care, advance directives, code status, and more. When appropriate, hospice discussions and referrals are initiated with these patients subsequently managed by the Pulmonary-Palliative NPs through the course of their progressive lung failure. The guidelines for the clinic's practice mission came from the ATS policy and consensus statements as well as from the National Consensus Project, which issued clinical practice guidelines (updated in 2018) for the delivery of quality palliative care for patients with advanced disease. These guidelines were not cancer-specific and included patients of any age living with progressive chronic conditions as well as those who are seriously and terminally ill. These are patients for whom intensive palliative care is the predominant focus for the remainder of their lives.[8,9,12,13,15–17]

Difficulty with managing the advanced lung disease patient is often due to the unpredictability of their illness and difficulties in prognostication.[8,21,27] The advantage of this clinic is that by integrating early discussions into their routine care, one can provide follow-up and continued dialogue across the continuum of the patient's disease trajectory. A barrier often encountered is that the delivery of palliative care has traditionally been viewed as a role for specialists, when (and as advocated by the ATS) it truly should be an integrated, fundamental component of comprehensive pulmonary care.[1,6,8]

There is a need for education and training for healthcare and social care professions to plan and provide high quality EOL care, and this is intensified in pulmonary medicine where patients have incurable, progressive illness with relatively high mortality and morbidity as disease advances.[6,8,9] Pulmonary-palliative care consults and ongoing care emphasize patient dignity, autonomy, and comfort. The first focus is to determine the patient/family understanding and goals. Part of this process is often early discussion and intervention for advanced illness planning in hopes of avoiding inappropriate medical interventions in favor of those that will not prolong a process of dying, but serve to prolong a process of living.[33,34]

If indicated, the Pulmonary-Palliative NPs arrange aggressive, state-of-the-art medical care for patients with advanced illness which may include measures such as high-flow nasal cannula, NIV, and continuous or bi-level positive airway pressure therapy. Underlying this is ongoing medical management and psychosocial support for patient, family, and caregivers. All too often, there is the need to dispel myths concerning mechanical ventilation, as most think death is swift and sudden or they will be unconscious if on life support. The experience of this clinic has beautifully demonstrated that human beings are adaptable—because patients control their breathlessness by decreasing what they do on a daily basis, they are surprised when told they have a life-limiting illness and should consider palliative care.

When assessing readiness or suitability for pulmonary-palliative intervention, there are various triggers we use embedded within our daily pulmonary medicine practice:

- The *BODE index* (*B*ody-mass index, airflow *O*bstruction, *D*yspnea, and *E*xercise) is a scored index used to assess patients with COPD to predict long-term outcomes for them.[35] The degree of airflow obstruction is determined by the forced expiratory volume percentage predicted after using a bronchodilator to open airways from the pulmonary function test, the dyspnea is as reported by the patient, and the exercise component is measured using a 6-minute walk test distance. While it should not be used alone to guide treatment, the BODE score is a helpful adjunct to promote early conversations about advancing lung disease, allowing a focused conversation on the reality of their prognosis using clinical evidence. In general, patients with a higher BODE are at increased risk of mortality and often have increased frequency of COPD exacerbations and hospitalizations. This score can be calculated with an online calculator: https://www.mdcalc.com/bode-index-copd-survival#creator-insights.
- The *GAP index* is a risk assessment system used for clinical prediction of prognosis in patients with IPF. Using the frequently measured clinical and physiologic variables of gender (*G*), age (*A*), and two lung physiology variables (*P*) (FVC and DLCO, described earlier), the GAP index provides an estimation of individual risk of mortality. This score can be easily determined using the online calculator: https://www.acponline.org/journals/annals/extras/gap/.

Tools like BODE and GAP assist in shaping prognostic conversations, but providers are encouraged to remember that end-stage lung disease patients, especially those with COPD, remain a notoriously difficult population to predict. Patients can lose ground with a viral illness and never regain it, or they can plateau and remain there for months, even years. Clinically, we also look at severity of lung function, frequency of exacerbations, need for oxygen, and declining functional status. Early identification and intervention is key because the symptom burden in severe COPD can be as high as in patients with lung cancer, but COPD patients may have a longer survival.[34] We continue usual management of dyspnea with opioids, inhaled medications, and oxygen. Even for those with respiratory derangement, doses of opioid are safe and effective. Other considerations include anxiety (a result of and contributor to breathlessness), depression, fatigue, and pain. Patients with end-stage lung disease have significantly impaired QOL and emotional well-being. Those with end-stage COPD have needs that are not as well met as patients with lung cancer, and, at times, their survival is shorter.[12,19,20,26]

The majority of patients seen in this clinic are those with COPD or ILD, a statistic that correlates with the national prevalence of COPD as the leading lung disease and ILD as a more fatal though less frequently occurring lung disease.[31] This clinic initiated a change in practice based on the rising national recognition of palliative care, access to palliative care for all chronic illness patients,[36] and, most specifically, the needs of advanced lung disease patients and their families.[8] It is the commitment of the providers to assure that all lung disease patients have access to high-quality palliative care earlier in their advancing disease trajectory. The projected outcome is to provide a more comprehensive paradigm of care for advanced lung patients. In essence, this clinic epitomizes a new construct, built to provide palliative care in conjunction with best practice guidelines for the care of advanced lung disease patients. We recognize this new construct/model has broad application potential for other chronic disease management clinics—as seen with similar models of palliative care delivery and the evidence established in oncology patient management.[9–12]

Case Study: A Patient with COPD

Mrs. C is an 85-year-old woman seen in clinic following admission for severe oxygen-dependent COPD with a past medical history of motor vehicle collision resulting in long-term sequelae of functional limitations and dysphagia with percutaneous gastric feeding tube. At baseline, she had dyspnea at rest and pulmonary function testing indicating lung function of 30% predicted. During her admission, it was discovered that she had elevated right heart pressures on echocardiogram, suggesting pulmonary hypertension; her right heart catheterization found no right or left heart dysfunction and no true pulmonary hypertension. She was unable to tolerate pulmonary rehabilitation due to the severity of her musculoskeletal complaints. She continued to decline, with progressive shortness of breath and frequent exacerbations which were not ameliorated with best-practice efforts and medical maximization. Due to continued decline in functional state, she was referred to the Pulmonary-Palliative clinic. At the initial visit, her chief complaint was increased cough and sputum. She was taking nectar-thick liquids, and a careful assessment of her intake revealed two cans of nutritional supplements but not much more hydration.

The Pulmonary Palliative NP added hydration via gastric tube, began daily airway clearance with a flutter device, and continued nebulizer therapies (initially, a recommendation to increase nebulizer frequency was made; however, the patient refused to escalate frequency of nebulizer due to the time factor). The Pulmonary-Palliative NP conducted ongoing advance illness planning discussions across multiple clinic visits, which included discussion of advance directives, code status, end-of-life care, and hospice education. Both the patient and her spouse expressed great relief at being able to begin this discussion. With continued visits, hospice was discussed further and code status was addressed: the patient was aware of her circumstances and verbalized satisfaction and happiness that she could be in control of her end-of-life decisions. Also during these visits, life and legacy reviews were conducted in conjunction with logotherapy—the patient shared that in her past she has been a performer who had at times worked on Broadway; during one memorable clinic visit she sang her favorite song, in a fair Irish brogue complete with gestures, from one of her performances. She called a few weeks later and elected hospice—which the Pulmonary-Palliative Medicine NP arranged in conjunction with her primary care office. During telephone visits with the Pulmonary Palliative NP, the patient expressed tremendous appreciation and gratitude for the focused care provided after inquiring about her wishes and preferences and for allowing her to share a part of herself that brought her extraordinary pride and joy. There was a reinforcement of her dignity with this—it was important that we knew her as a person, from the time before she was a “patient.” With several weeks of attentive hospice and palliative care, she died at home, in peace and comfort, holding her husband’s hand.

Conclusion

The advanced lung disease patient suffers from multifaceted symptoms which, in combination, contribute to a loss in QOL, emotional distress, and, perhaps the most egregious loss of all, their functional independence. Preserving the dignity of the advanced lung disease patient with early palliative care interventions, strong symptom management, and comprehensive management of their global needs will lead to true optimization of patient care and well-being. As Rachel Naomi Remen once said: “Our power to heal is far less limited than our power to cure. Healing is not a relationship between an expert and a problem . . . it is a relationship between human beings.”[37] In nursing, the art of our work, with its essence of caring and compassion, should remain the foundational core of all our actions when engaging in the care of others.

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CHAPTER 47

Palliative Care in Heart Failure

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Key Points

- The heart failure disease trajectory is progressive although highly unpredictable, with periods of high function interspersed with sudden life-threatening exacerbations leading to emergent hospitalizations and often rapid deterioration and death.
- The focus of supportive care is on promoting positive health behaviors (diet, exercise, and smoking cessation) and symptom management, particularly shortness of breath, fatigue, and leg swelling.
- Management of advanced heart failure is treated with medicines and devices to sustain adequate circulation and prevent life-threatening arrhythmias.

Introduction

Heart failure is a complex syndrome resulting from any functional or structural disorder of the heart that lowers the ability of the heart to pump blood and/or leads to systemic or pulmonary congestion.[1] Heart failure is not a disease, but a syndrome, and hence diagnosis relies on a myriad of clinical indicators and functional ability assessment. Since the 1970s, heart failure in the US has been described as an epidemic as newer therapies have increased survival.[2,3] Heart failure can be a slowly developing condition that results from coronary artery disease, hypertension, diabetes, and valvular disease or one that develops precipitously after a myocardial infarction.[4] Those living with symptomatic heart failure experience lower quality of life (QOL) and high morbidity and mortality; however, advances in therapies including angiotensin converting enzyme (ACE) inhibitors, beta blockers, coronary revascularization, implantable cardioverter-defibrillators, and cardiac resynchronization have substantially improved outcomes for patients.[3,5]

An estimated 6.5 million Americans and 37.7 million individuals worldwide are affected by heart failure.[1,6] In the United States, there are 960,000 new cases of heart failure each year and just over 300,000 deaths.[1] It is estimated that, by 2030, the number of Americans with heart failure will increase to 8 million.[7] African Americans have the highest incidence of heart failure, followed by Hispanic, white, and Chinese Americans, with many of these differences mediated by differences in hypertension, diabetes, and low socioeconomic status.[1] The morbidity and symptom burden due to heart failure is often high. Nearly 3 in 4 suffer from at least one comorbidity, the most prevalent of which include chronic kidney disease, anemia, diabetes, and chronic obstructive pulmonary disease (COPD).[8]

The toll of heart failure on economic and healthcare utilization resources is considerable.[9] Worldwide, the economic cost of heart failure has been estimated at $108 billion per year.[9] In the United States, medical costs directly related to heart failure amounted to $20.9 billion in 2012,[5] with estimates predicting an increase to $53 billion in 2030.[7] These costs nearly triple in the last 3 months of life, mostly due to increased number and length of hospitalizations.[10] Indeed, periodic exacerbations of heart failure require intensive treatments that nearly always require hospitalization. Close to 1 million hospitalizations occur each year due to heart failure, and it is the leading cause of hospitalization for individuals 65 years of age and older in both the United States and Europe.[2,6]

To help persons and families affected by heart failure manage the high symptom burden, complex decision-making, and ever-present risk of exacerbation and death, the early integration of palliative care is critical and has been recommended in numerous organizational statements in both the United States and worldwide.[11–19] Palliative care in the setting of heart failure seeks to mitigate complex symptoms and maximize function; promote positive coping, psychological health, and spiritual behaviors; enhance communication and decision-making; facilitate prognostic understanding and advance care planning; and coordinate care, including transitions to hospice care when appropriate. To describe the role of palliative care further, this chapter provides an overview of the palliative care aspects of heart failure care.

Heart Failure Pathogenesis

Cardiac output is the primary indicator of cardiac performance. It equates to the product of the number of beats per minute (heart rate) and how much blood the heart pumps with each beat (stroke volume). *Heart rate* increases through activity of the sympathetic nervous system that speeds up the heart and is decreased by the parasympathetic nervous system. *Stroke volume* is determined by preload, afterload, and myocardial contractility. *Preload*, also called *end-diastolic volume*, is the amount of blood present in the ventricle at the end of diastole just prior to the heart pumping (or systole). As preload increases, myocardial muscle fibers stretch and eject with a proportionate force according to the Frank-Starling mechanism.

The fraction of blood ejected by the ventricle relative to the preload is called *ejection fraction* and is the most commonly used metric for assessing heart failure. *Afterload* is the amount of resistance against which the ventricles must contract in order to eject blood and is a function of systemic vascular resistance and ventricular wall tension. The higher the systemic vascular resistance, the more forceful the systolic contraction must be to push blood out of the ventricle. *Contractility*, or *inotropy*, is the ability of the heart muscle fibers to contract against a load in the atria and ventricles. Myocardial contractility is governed at the cellular level by calcium ions (Ca^{++}) and the sodium-Ca^{++} exchange pump, hence many drugs for heart failure affect these cellular mechanisms.

Heart Failure with Reduced Versus Preserved Ejection Fraction

Based on measurement of the left ventricular ejection fraction (LVEF), heart failure is most commonly characterized as having reduced (≤40%) or preserved LVEF (≥50%). In *heart failure with reduced LVEF* (HFrEF) (also referred to as systolic dysfunction), myocardial contractility has been weakened, resulting in a lower ejection fraction and cardiac output. Primary causes of HFrEF include coronary artery disease, hypertension, ischemic heart disease (i.e., myocardial infarction or ischemia with associated ventricular remodeling), and valvular disease (e.g., aortic stenosis). Common co-occurring conditions are supraventricular tachycardias (e.g., atrial fibrillation), ventricular arrhythmias, bradycardia, venous thromboembolism, anemia, and sleep disruption.

In contrast, and occurring in fewer cases, *heart failure with preserved LVEF* (HFpEF) (also called diastolic dysfunction) retains a normal ejection fraction (40–65%) but the ventricles are stiff, less compliant, and unable to stretch normally. Consequently, venous blood returning from systemic circulation is unable to adequately fill the ventricles, thereby compromising preload and reducing stroke volume. As heart rate increases, diastolic filling time decreases, and hence, HFpEF worsens with tachycardia. Common causes of HFpEF are those that impede expansion of the ventricle (e.g., pericardial effusion, constrictive pericarditis), those that increase myocardial wall thickness and reduce chamber size (e.g., hypertrophic cardiomyopathy), and those that slow diastolic relaxation (e.g., ischemic heart disease). Resultant co-occurring conditions mirror that of heart failure with reduced LVEF.

Right Versus Left Ventricular Dysfunction

Heart failure can be classified according to whether the right or left ventricle is primarily affected (although both ventricles are typically affected over the long term). Right ventricular heart failure is the inability of the right ventricle to move deoxygenated venous blood from systemic circulation into the pulmonary circulation. Major effects include dependent peripheral edema, reduced left ventricular cardiac output, and hepatomegaly due to blood backing up into the hepatic veins. If hepatic circulation remains congested for a prolonged period, blood will begin engorging the spleen and the gastrointestinal tract resulting in decreased hepatocellular function, ascites, altered nutritional uptake, and gastrointestinal discomfort. The most common cause of right ventricular heart failure is left ventricular heart failure. Other causes include chronic pulmonary hypertension (also called cor pulmonale) due to thromboembolic disease or structural lung disease, tricuspid or pulmonic valve stenosis or regurgitation, right ventricular infarction, cardiomyopathy, and congenital heart defects (e.g., Tetralogy of Fallot, ventricular septal defect).

Left ventricular heart failure occurs when oxygenated blood from the pulmonary circulation is not effectively pumped into systemic circulation. This lower cardiac output results in blood backing up into the left ventricle, left atrium, and the pulmonary circulation. Consequently, pulmonary capillary pressures increase and, if high enough, cause intravascular fluid to infiltrate the lung interstitium resulting in impaired gas exchange (i.e., hypoxia) and pulmonary edema. The most common causes of left ventricular heart failure are hypertension and myocardial infarction. Aortic or mitral valve stenosis or regurgitation may also cause this type of heart failure.

Disease Trajectory and Prognosis

Illness Trajectory

The heart failure disease trajectory is progressive yet highly unpredictable, with periods of high function interspersed with sudden life-threatening exacerbations leading to emergent hospitalizations and sometimes rapid deterioration and death. For many, heart failure begins with an emergent presentation to the emergency department with severe breathlessness and chest pain or discomfort (e.g., acute myocardial infarction); for others, the onset is gradual with increasing breathlessness and fluid retention that might be first evaluated by a primary care provider. Though depending on the severity of the initial insult, medications combined with lifestyle modifications (e.g., low-sodium diet, increased physical activity, weight loss) and fluid management can effectively ameliorate nearly all symptoms, helping patients reach a state of near-baseline functioning that can potentially last several years. As heart failure progresses, however, symptoms begin to reoccur that require management beyond medication therapy and include consideration of implantable cardiac devices, such as pacemakers and left ventricular assist devices. How people die with heart failure varies considerably. For some, a spontaneous cardiac event, such as a lethal arrhythmia, can occur unexpectedly and result in rapid deterioration and sudden death. For others, the dying phase is prolonged due to progressive pump failure marked with episodes of acute decompensation and severe symptoms.

Classification

Two classification systems are most commonly used to grade the severity of heart failure: the American College of Cardiology/American Heart Association (ACC/AHA) Stages and the New York Heart Association (NYHA) Classes (see Table 47.1).

The two classification systems have some similarities; however, the ACC/AHA system includes criteria for both physical symptoms and structural abnormalities of the heart, whereas the NYHA system only includes physical symptom criteria. An individual's NYHA class can fluctuate based on clinical status, but their ACC/AHA Stage progresses unidirectionally; hence, one's stage and class are not direct corollaries of one another.

Estimating and Communicating Prognosis

Estimating and communicating prognosis in heart failure is critical to help patients and families plan and make decisions about treatment. However, accurate prognosticating is extremely difficult due to the interactions of frailty, polypharmacy, and comorbidities (the average patient is on nine medications and has

Table 47.1 Classification systems for heart failure and typical treatments[15,16,29]

ACC/AHA heart failure stages		NYHA heart failure classes		Typical treatments
Stage A (At risk)	No limitations or symptoms of HF. No structural heart abnormalities. Often presence of hypertension, diabetes, coronary artery disease, and metabolic syndrome.	No comparable class		Lifestyle changes including regular exercise, smoking cessation ACE inhibitor or ARB if confirmed coronary artery disease, diabetes, and hypertension Beta-blockers if post-myocardial infarction or hypertension
Stage B (Asymptomatic)	No limitations or symptoms of heart failure. Structural heart abnormalities present (e.g., left ventricular hypertrophy or other evidence of remodeling). Decreased ejection fraction. Often subsequent to myocardial infarction, valvular disease, and/or cardiomyopathy.	Class I	No limitations of physical activity. Ordinary physical activity does not cause fatigue, dyspnea, or palpitation.	ACE inhibitor or ARB Beta-blockers if post-myocardial infarction Aldosterone inhibitor if the symptoms continue while taking beta-blockers and ACE/ARB medications Surgery for coronary artery repair and valve repair or replacement Implantable cardiac defibrillator (ICD)
Stage C (Symptomatic)	Shortness of breath, fatigue, and activity intolerance with activities of daily living. Structural heart abnormalities present.	Class II	Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity causes fatigue, dyspnea, and/or palpitation.	ACE inhibitors and beta-blockers Hydralazine/nitrate combination if symptoms persist Diuretics and digoxin if symptoms persist Aldosterone inhibitor if symptoms severe and other medications have been initiated ARBs and neprilysin inhibitors Biventricular pacemaker Implantable cardiac defibrillator
		Class III	Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, dyspnea, and/or palpitation (e.g., walking distances of 20–100 meters).	
Stage D (End-stage)	Presence of progressive and/or persistent severe signs and symptoms of heart failure driven primarily by the heart failure syndrome itself despite optimal medical, surgical, and device management.[19] Frequent hospitalization, severely limited exertional tolerance, and poor quality of life are typically present.	Class IV	Physical activity not possible without discomfort. Heart failure symptoms at rest.	Strict fluid and sodium restriction Surgery (e.g., valve replacement) Heart transplantation Ventricular assist devices Continuous intravenous inotropic support

Source: From References 15, 16, 29.

ACE, angiotensin converting enzyme; ARB, angiotensin II receptor blocker.

four or more comorbidities),[20,21] discerning treatment-responsive from treatment-nonresponsive situations, and wide variations in end-of-life events.[17] While survival has improved since the 1970s,[3] approximately 25% of individuals newly diagnosed with heart failure will die within 1 year and 50% within 5 years. However, these rates vary by age and type of heart failure, with individuals 80 years of age or older and those with HFrEF experiencing the highest mortality rates.[22,23] It is also important to note that about half of heart failure deaths are due to complications of comorbidities, particularly respiratory conditions and cancer.[22,24]

Despite the challenges in accurate prognostication, recommendations in the current literature suggest using a combination of objective risk models and clinical gestalt.[12] The Seattle Heart Failure Model (SHFM) and the Meta-Analysis Global Group in Chronic Heart Failure (MAGGIC) risk calculators are well-validated multivariable models and are available online (https://depts.washington.edu/shfm/ and http://www.heartfailurerisk.org). While predicting death in heart failure using these models is imperfect, predicting *nonsurvival* outcomes of importance to patients and families—such as QOL, symptom burden, and rehospitalizations—using prognostic models is even poorer.[25,26]

Despite the many challenges to accurate prognosis, prognostic assessments are recommended yearly and subsequent to hospitalization and stabilization after major health changes and events.[12] Such events represent “inflection points” that warrant reappraisal of goals of care, patient and family preferences, and treatment modalities. Approaches to “serious illness,” “bad news,” and “prognosis” conversations are covered in greater depth elsewhere,[27,28] and the palliative care nurse clinician is encouraged to continually enhance skills and prepare in advance for these conversations.

Overview of Assessment and Medical Management in Stage D Heart Failure

A number of major guidelines are published and regularly updated for the treatment of advanced Stage D heart failure, including the 2013 American College of Cardiology/American Heart Association guideline with 2017 focused update,[15] the Canadian Cardiovascular Society guidelines, the 2016 European Society of Cardiology guidelines,[16] and the National Institute for Health and Care Excellence chronic heart failure guideline (available at http://pathways.nice.org.uk/pathways/chronic-heart-failure). The following overview of heart failure clinical assessment and treatment is consistent with these guidelines.

Health History

Important health history information to collect during assessment includes:

- History of present illness including heart failure progression history and precipitating factors for most recent episode
- Heart failure risk factors and preventive behaviors (e.g., exercise, weight loss)
- Exacerbation episodes and hospitalizations
- Current and past treatments, therapy response, and compliance
- History of physical (e.g., diabetes, COPD, dyslipidemia) and psychosocial (e.g., anxiety, depression) comorbid conditions
- Symptom assessment, particularly dyspnea, fatigue, pain, edema, anorexia and cachexia, depression, and anxiety, focusing on exacerbating and relieving factors (see section on "Management of Symptoms in Stage D Heart Failure")
- Patient and family's understanding of the illness and prognosis, to date, as well as current goals for care and treatment preferences
- Spiritual and faith-based practices and beliefs that may impact care

Physical Exam

The physical exam should begin with assessment of vital signs, height and weight, overall appearance, and mood/affect. In general, physical exam findings in heart failure lack sensitivity; however, a head-to-toe assessment may be remarkable for several of the following findings:[29]

- *Blood pressure and heart rate*: Tachycardia and systolic blood pressure less than 90–100 mm Hg is common if treatment is suboptimal. Presence of a weak, thready pulse and/or pulsus alternans (alternating strong and weak pulse) may indicate decreased cardiac output.
- *Jugular venous distension*: Assessed with the patient supine at a 45-degree angle. A distance of more than 3 cm between the sternal angle and the top of the internal jugular venous pulsation is a specific but not sensitive sign of elevated left ventricular filling.
- *Point of maximal impulse*: Assessed with finger palpation, the point of maximal impulse is typically located at the midclavicular line at the fifth intercostal space. Presence of cardiomegaly will shift this point laterally and downward.
- *Third and fourth heart sounds*: One or both of these heart sounds are present in nearly all cases of heart failure.
- *Pulmonary assessment*: Auscultation often reveals rales and/or wheezing. In some cases, increased lymphatic drainage compensates for increased pulmonary congestion over time.
- *Liver size and hepatojugular reflux*: Hepatomegaly may present in right-sided heart failure and can be assessed using the hepatojugular reflux. With the patient supine at a 45-degree angle and instructed to keep the mouth open (to prevent Valsalva maneuver), moderate pressure is applied to the middle of the abdomen for 30–60 seconds. Hepatojugular reflux is present if the height of the neck veins increases by 3 cm or more and remains increased during compression of the abdomen.
- *Lower extremity edema*: Usually detectable when the extracellular volume exceeds 5 L. The edema may be accompanied by stasis dermatitis, a chronic, eczema-like condition characterized by edema, hyperpigmentation, and sometimes ulceration.

Laboratory Data and Diagnostic Tests

Laboratory data and diagnostic tests are often performed prior to palliative care evaluation. Relevant tests and data to assess in relevance to heart failure include:

- *Hypokalemia*: Possibly due to thiazide diuretics.
- *Hyperkalemia*: Possibly due to potassium-sparing diuretics and ACE inhibitors.
- *Elevated blood urea nitrogen (BUN) and creatinine*: Consider prerenal azotemia related to pump failure and decreased renal perfusion.
- *Elevated liver enzymes, including serum transaminase and bilirubin*: Potentially hepatic congestion from right-sided (or left-sided) heart failure. Jaundice may be present. In cases of chronic hepatomegaly, cardiac cirrhosis may occur, signaled by hypoalbuminemia, hypoglycemia, and increased prothrombin time.
- *Decreased hemoglobin*: May indicate (1) normocytic anemia secondary to decreased production of erythropoietin (and thus decreased red blood cell production) due to chronic kidney disease (comorbid kidney disease is present in 20–40% of heart failure patients) and/or (2) anemia secondary to hemodilution through plasma volume expansion triggered by the renin-angiotensin system.
- *Elevated cardiac biomarkers including B-type natriuretic peptide (BNP), and N-terminal pro-B-type natriuretic peptide (NT-proBNP)*: Abnormally high levels typically indicate presence of acute and/or chronic heart failure and can be used to assist in diagnosis or exclusion of heart failure as a cause of symptoms (e.g., dyspnea, weight gain), inform prognosis, and estimate the likelihood of hospital readmission. Utility may be limited with concurrent renal failure.[15]
- *Electrocardiogram (ECG)*: Abnormalities in advanced heart failure are typically present and may indicate atrial and ventricular arrhythmias, heart block and other conduction problems due to electrolyte disturbances, ischemia (new and old infarctions), and cardiac remodeling.
- *Echocardiography*: Used to assess left ventricular size, mass, and function; valve function; regional wall motion; and ACC/AHA heart failure staging. Also allows for the estimation of ejection fraction.

- *Chest radiograph*: Can be used to evaluate heart size, pulmonary edema, and pleural effusions.
- *Cardiac catheterization*: Assesses coronary artery occlusion and pressure gradients across heart valves. Can also be used as a platform for stent placement of occluded vessels. Right-sided catheterizations can assess pressures on the right side of the heart and pulmonary pressures.
- *Stress test*: Used to assess cardiac function in response to external stress induced through either physical exertion (e.g., walking on a treadmill, pedaling on an exercise bicycle) or intravenous medications (e.g., adenosine).[30]

Treatment

Pharmacologic Treatment

Table 47.2 lists commonly used medications in the management of advanced heart failure by class. The primary goals of pharmacologic management are to improve cardiac function and reduce symptoms. While pharmacologic therapies can improve a

Table 47.2 Common medications in heart failure

Medications	Dose routes and ranges	Side effects	Special considerations
Angiotensin converting enzyme inhibitors (ACE inhibitor)			
Captopril	6.5–50 mg three times a day PO	**Hyperkalemia; dizziness;** cough; less frequent: pruritus, skin rash, taste loss (dose-related and reversible); agranulocytosis, renal impairment, angioedema	Frequent urinary/blood analysis needed. Monitor liver enzymes. Do not use in patients with history of angioedema or patients taking aliskiren with diabetes, lithium, gold, or mTOR inhibitors (sirolimus). Caution with patients with renal insufficiency. Dose adjustment required for hemodialysis.
Enalapril	2.5–20 mg twice a day PO		
Lisinopril	2.5–40 mg daily PO; 2.5 mg starting dose with hyponatremia or creatinine clearance <30 mL/min		
Angiotensin II receptor blockers (ARB)			
Losartan	25–150 mg daily PO; recommended hepatic initial dose: 25 mg PO daily	**Cough; dizziness; muscle ache**; hypotension; renal insufficiency; hyperkalemia	Caution with patients with low systemic blood pressure. Caution with concomitant use of potassium-sparing diuretics or NSAIDs. Do not use in diabetic patients taking aliskiren. Caution with patients on lithium—monitor serum lithium levels.
Valsartan	20–160 mg twice daily PO		
Angiotensin receptor-nephrolysin inhibitor			
Sacubitril/Valsartan	49/51–97/103 mg twice daily PO; 24/26 mg starting dose for patients ACE inhibitor/ARB naïve, creatinine clearance <30 mL/min, or moderate hepatic impairment	**Hypotension**; **hyperkalemia**; dizziness; renal insufficiency; angioedema	Not all doses tested in HF trial. 36-hour wait period switch to/from ACE inhibitor. Risk of angioedema. High cost due to lack of generic availability—might not be covered by some insurances. Do not use in diabetic patients taking aliskiren.
Loop diuretics			
Furosemide	20–80 mg daily PO	**Hypotension; dry mouth**; muscle pain/cramps; hyperglycemia; dermatitis; tinnitus; systemic vasculitis; pancreatitis	Do not use in patients with anuria or those taking aminoglycoside antibiotics or ethacrynic acid (ototoxicity). Caution with patients with sulfonamides allergy. Caution with patients with hepatic cirrhosis, ascites. Caution with digitalis—may exaggerate hypokalemic metabolic effect.
Bumetanide	0.5–10 mg daily PO	**Muscle cramps; dizziness**; hypotension; hypokalemia; ototoxicity; pruritus; EKG changes; thrombocytopenia	Do not use in patients taking Indomethacin. Caution in patients with hepatic impairment or allergic to sulfonamides. Caution with patients on lithium—monitor serum lithium levels.
Thiazide diuretics			
Metolazone	2.5–20 mg daily PO	**Dizziness; hypotension; fatigue; electrolyte disturbances**; agranulocytosis; hepatitis; necrotizing vasculitis; seizures	Do not use in patients with anuria. Caution in patients with hyperglycemia or taking NSAIDs, digitalis glycosides, lithium.
Chlorothiazide	250–500 mg twice daily PO	**Photosensitivity; hyperglycemia; gastrointestinal distress; dizziness**; agranulocytosis; pancreatitis; hepatic impairment; renal failure	Do not use in patients with anuria. Caution in patients with hyperglycemia or taking NSAIDs, digitalis glycosides, lithium.
Hydrochlorothiazide	25 mg once or twice daily PO	**Hypotension; dizziness; phototoxicity**; hyperglycemia; electrolyte disturbances; pancreatitis; glaucoma; renal impairment	Do not use in patients with anuria or taking dofetilide (risk of QT prolongation). Caution in patients with hyperglycemia or taking methotrexate, cyclophosphamide, NSAIDs, digitalis glycosides, lithium.

(continued)

Table 47.2 Continued

Medications	Dose routes and ranges	Side effects	Special considerations
Chlorthalidone	12.5–100 mg once daily PO	**Hyperuricemia**; cardiac arrhythmias; pancreatitis; pulmonary edema	Do not use in patients with anuria. Caution in patients with hyperglycemia or taking NSAIDs, digitalis glycosides, lithium.
Aldosterone antagonists			
Spironolactone	25–50 mg daily PO; starting dose of 12.5 mg/day for patients with creatinine clearance 30–50 mL/min	**Hyperkalemia; dizziness**; hypotension; gynecomastia; renal dysfunction; leukopenia	Do not use in patients with anuria, Addison's disease, hyperkalemia, or taking other potassium sparing diuretics. Caution in patients with hepatic impairment, or taking NSAIDs, cholestyramine, heparin, lithium, trimethoprim.
Eplerenone	25–50 mg daily PO	**Hyperkalemia; renal dysfunction;** angina; myocardial infarction	Do not use in patients with hyperkalemia, or taking other potassium-sparing diuretics. Caution in patients taking strong CYP3A4 inhibitors (clarithromycin, itraconazole, ketoconazole).
Cardiac glycosides			
Digoxin	0.25 mg daily PO or IV; 0.0625–0.125 mg daily for patients with renal impairment; use with caution in age >70 years	**Bradycardia; gastrointestinal distress**; headache; yellow vision	Use with caution in patients taking amiodarone, cholestyramine, cyclosporine, erythromycin, loop diuretics, metoclopramide, methotrexate, oral aminoglycosides, thiazide diuretics, thyroid hormone, or verapamil.
Beta-blockers			
Metoprolol succinate extended release	12.5–25 mg daily PO	**Dizziness**; **bradycardia**; **fatigue**; bronchospasm; exercise intolerance; gastrointestinal distress; laryngospasm; paresthesia; hypoglycemia unawareness	Do not use in patients with second- or third-degree AV block, severe sinus bradycardia. Taper to discontinue. Caution in patients with renal impairment or patients taking cimetidine, clonidine, epinephrine, hydralazine, lidocaine, NSAIDs, prazosin, rifampin, verapamil.
Carvedilol (also has alpha-blocker properties)	3.125–50 mg twice daily PO for 2 weeks; may adjust starting dose with patients with hepatic impairment	**Bradycardia**, bronchospasm; hepatic injury; tinnitus; constipation; fatigue; headache; hypoglycemia unawareness	Do not use in patients with second- or third-degree AV block, severe sinus bradycardia. Taper to discontinue. Frequently monitor serum glucose level in diabetic patients. Caution in patients taking amiodarone, clonidine, cyclosporine, digoxin, diltiazem, rifampin, verapamil.
Bisoprolol	1.25–10 mg daily PO	**Bradycardia**; rhinitis; gastrointestinal distress; fatigue; headache; hypoglycemia unawareness	Do not use in patients with second- or third-degree AV block, severe sinus bradycardia. Taper to discontinue. Frequently monitor glucose level in diabetic patients. Caution in patients taking anticholinergics, hormonal contraceptives, insulin, NSAIDs, prazosin, aspirin.
Vasodilators (Combination Hydralazine + Isosorbide Dinitrate indicated for HF)**			
Isosorbide Dinitrate**	25–50 mg four times daily PO	**Headache**; dizziness; hypotension; rebound hypertension; tachycardia; weakness	Need to be taken with hydralazine for heart failure. Not for acute angina episodes. Headache common upon discontinuation. Potential for nitrate tolerance. Do not use in patients taking phosphodiesterase inhibitors (Viagra, etc.) or soluble guanylate cyclase (Riociguat). Caution in patients taking calcium channel blockers.
Hydralazine**	20– 30 mg four times daily PO	**Tachycardia; palpitations;** anorexia; headache; back, arm, or chest pain; shortness of breath; blood dyscrasias	Need to be taken with isosorbide dinitrate for heart failure. Not for acute angina episodes. Caution in patients with renal insufficiency or lupus or patients taking adrenergic blockers.

Source: From References 15, 63.

Bolded side effects are most common;

Common medications as indicated by the 2013 ACCF/AHA Heart Failure Guideline & 2017 ACC/AHA/HFSA Focused Update of the 2013 Guideline; typical dose ranges provided; dosing for patients is dependent on individual health status, comorbidities, and institutional recommendations; Consultation with pharmacy is recommended.

patient's clinical status and symptoms, underlying cardiac structure and function are not restored to normal states. As heart failure worsens, a patient's condition may become refractory to maximal doses of medications, prompting consideration of surgery, mechanical circulatory support devices, and heart transplant options.

Lifestyle Recommendations

While evidence for the impact of lifestyle modifications on morbidity and mortality in advanced heart failure is limited to observational studies, patients with advanced heart failure should be generally encouraged to (a) quit smoking, (b) limit or abstain from alcohol intake and illicit drug use, (c) restrict sodium intake to 1,500 mg/day, (d) restrict fluid intake to 1.5–2 L/day (patients with HFrEF), (e) lose weight if obese, and (f) monitor daily weight to track fluid retention and overload.

Implantable Cardioverter-Defibrillators

Implantable cardioverter-defibrillators (ICDs) are medical devices implanted inside the body that perform cardioversion and/or defibrillation upon detection of a lethal arrhythmia (e.g., ventricular fibrillation, ventricular tachycardia). The benefits of ICDs are most frequently observed in terms of prolonged survival in patients who have HFrEF and are at risk for sudden cardiac death. The devices alone do not improve cardiac function and are not recommended for patients with diastolic dysfunction or for patients with poor functional status and a prognosis of less than 1 year. ICDs are also not recommended for NYHA Class IV patients with medication-refractory congestive heart failure who are not candidates for heart transplantation. Patients should be informed *prior to ICD placement* about the option to deactivate the device as they approach end of life.[17]

Mechanical Circulatory Support

For patients with HFrEF who are symptomatic despite optimal pharmacological management, mechanical circulatory support devices (MCSD), including left ventricular assist devices (LVADs) and total artificial hearts (TAHs), may be viable options to partially or completely replace the function of the heart. The field of MCSD support is rapidly evolving, with numerous clinical trials in process and devices in queue for testing and approval. MCS is considered an approach that can bridge a patient to recovery, heart transplantation, and medical stabilization so that optimal decision-making can occur. LVADs are also used as a *destination therapy*, where the device's goal is to improve functional status and QOL for those who will not be considered for heart transplantation. Considerations for placement of a MCSD include (but are not limited to) type and severity of heart failure, likelihood of potential complications, presence of significant comorbidities, ability to tolerate long-term anticoagulation, adequate psychosocial and family caregiver support, and feasibility of future heart transplantation. The most recent guidelines, published in 2013 by the International Society of Heart and Lung Transplantation, recommend palliative care consultation for any patient being considered for MCSD as destination therapy.[13] Furthermore, the US Joint Commission now requires that a palliative care specialist be part of accredited LVAD destination therapy programs.[31] Palliative care nurses working frequently with the MCSD population should consult the most recent MCS clinical guidelines as well as seek more detailed guidance in working with patients and families considering and living with MCSDs.[32–35]

Heart Transplantation

Patients receiving heart transplantations have a median survival of 10 years and typically experience marked improvement in functional capacity. While heart transplantation may be a viable option for eligible patients with advanced heart failure, this option is constrained by the relatively limited number of donor hearts, the contraindications in patients with comorbidities, and the risk of posttransplant complications.[1] Patients considering transplantation should be made aware of the tradeoffs involved, including the risks of organ rejection and side effects of immunosuppression,[12] the details of which can be found in the most recent clinical guidelines.[36]

Intravenous Inotrope Therapy

Intravenous inotrope therapy, using medications such as dobutamine and milrinone, is initiated in the inpatient setting to stabilize heart failure patients with decompensation not improving to decongestive treatment with diuretics. While many patients are able to wean off these mediations, others become dependent and must consider either chronic intravenous inotrope therapy that is managed in the community setting or another destination therapy (e.g., heart transplantation, LVAD). Before decisions are made to receive chronic continuous infusions for symptom relief, patients' and families' treatment and prognostic understanding should be assessed, and they should be guided in goals of care discussions. Nearly all patients on home inotrope therapy die within 1 year.[37,38]

Renal Replacement Therapies

For heart failure patients with symptomatic fluid overload that is refractory to diuretic therapy, hemofiltration or hemodialysis can provide relief of symptoms. Generally, this occurs when patients have concurrent renal failure and require intermittent hemodialysis for clearance of nitrogenous toxins, maintenance of electrolyte status, and management of volume status. However, in severe cases of volume overload, hemofiltration is used to manage excess volume even if glomerular filtration and electrolyte balance remain preserved. This has been shown in clinical trials to improve outcomes for some over intravenous diuretics.[39]

Management of Symptoms in Stage D Heart Failure

Patients with Stage D heart failure often experience multiple symptoms that can compromise function and reduce QOL. In the following sections, palliative care considerations in managing some of the most commonly encountered symptoms in advanced heart failure are summarized; however, nurses are encouraged to refer to cited and other material for further clinical guidance.

Dyspnea

When the heart is unable to effectively pump blood forward into systemic circulation, the lung vasculature can become congested, impairing gas exchange and making breathing difficult.[40] This makes dyspnea one of the most common symptoms experienced in heart failure and has been reported to affect up to 88% of heart failure patients in the last 6 months of life.[41] Dyspnea management focuses on reducing fluid overload through prudent diuretic use, fluid and sodium restriction, and optimization of cardiac performance.[17] For HFrEF, ACE inhibitors, angiotensin II receptor blockers (ARBs), and mineralocorticoid antagonists can be considered for optimizing volume status chronically. Digoxin and intravenous inotropic agents (e.g., milrinone, dobutamine) are also commonly initiated and titrated to relieve symptoms. First-line adjunctive therapies include low-dose opioids (e.g., morphine, hydromorphone, oxycodone) that can be used safely with careful monitoring. Hydromorphone or oxycodone are safer short-acting agents than morphine or codeine for patients with compromised kidney function, given that the risk is less of accumulating toxic metabolites. For chronic use, transdermal fentanyl and oral methadone should be considered with appropriate monitoring for side effects. Oxygen should be administered only if patients become hypoxemic (oxygen saturation less than 88%), and benzodiazepines are considered if patients experience dyspnea-related anxiety.[42]

Fatigue

Reduced cardiac output results in diversion of blood away from skeletal muscles, interference in waste product removal, deconditioning and cachexia, poor sleep, depression, and decreased red blood cell production.[40] For all these reasons and others, fatigue is one of the most common symptoms in heart failure and yet it is one of the most underassessed and undertreated. Treatment should be focused on optimizing cardiac performance, exercise as tolerated, energy conservation, sleep hygiene, and nutritional support and in identifying concurrent comorbid contributors such as hypothyroidism.[43] Corticosteroids (e.g., dexamethasone 2–8 mg/day) may be considered for short-term relief (i.e., 4–6 weeks) but caution is warranted due to potential for fluid overload; it may be of limited benefit in patients with longer prognoses.[40] Modafinil and methylphenidate may be beneficial in the treatment of fatigue, but more research is needed.[43]

Pain

Pain attributable to underlying heart failure includes pressure from edema (especially in the legs below the knees), anginal pain, and musculoskeletal pain from decreased perfusion, immobility, and deconditioning.[40,44] Approaches to pain should generally follow the World Health Organization analgesic ladder; however, in one study, the only medication reported to provide relief was opioids.[44] Given the high prevalence of comorbidities in heart failure patients, causes of pain should also be assessed that are non–heart failure related, such as arthritis and diabetic neuropathy. Nonsteroidal anti-inflammatory drugs, whether nonselective or COX-2 specific, are generally contraindicated in heart failure due to risk of renal failure, worsening of sodium and water retention, and increased risk of stroke and myocardial infarction. Opioids are appropriate for moderate to severe pain; however, careful monitoring of opioid-induced hypotension (particularly when patients are intravascularly hypovolemic) is prudent, especially if coadministered with benzodiazepines.[45] Methadone and buprenorphine may prolong QTc and thus ECG monitoring at baseline and following dose titration is warranted.[45]

Edema

Edema is a nearly universal sign in heart failure. The site of edema can vary depending on the type of heart failure. In right-sided failure, fluid accumulates in the lower extremities and often produces ascites. In left-sided failure, pulmonary edema and pleural effusions may result, potentially causing dyspnea and respiratory distress. Adding to the obstructive effects of underperforming ventricles, edema may result from underperfused tissues that activate the sympathetic and renin-angiotensin systems, thereby promoting sodium and water retention and plasma volume expansion. Therapeutic approaches include optimizing cardiac performance, diuresing excess fluid, and restricting sodium and fluid intake.[40] Nonpharmacologic interventions include lower extremity elevation, use of compression stockings, and paracentesis and thoracentesis for relief of refractory ascites and pleural effusions, respectively.

Cachexia

Cachexia is a poor prognostic indicator in heart failure and is defined as a 6% or greater loss in nonedematous total body weight over a 6-month period.[46] The mechanisms of cardiac cachexia are not fully understood but appear to be multifactorial and mediated by changes in endocrine function, insulin uptake, nutritional malabsorption in the gut, catecholamines, cortisol, natriuretic peptides, and pro-inflammatory cytokines.[46–48] Management includes optimizing nutrition and exercise as tolerated. There are no approved medications for cardiac cachexia; however, there may be some protective benefit of ACE inhibitors and beta blockers; more information can be found in cited reviews.[46,48]

Depression

While estimates vary, approximately 40% of patients with advanced heart failure experience depression,[49] which has been associated with poorer medication adherence and other outcomes in this population,[49] including higher mortality.[50] Treatment approaches include cognitive behavioral therapy, spiritual support, and medications.[51] First-line medications include low-dose selective serotonin reuptake inhibitors (SSRIs; e.g., sertraline[52]); however, these drugs can result in fluid retention, hyponatremia, and may prolong the QTc interval.[53] Other medication options include selective serotonin norepinephrine reuptake inhibitors (SNRIs) and psychostimulants (e.g., methylphenidate), but tricyclic antidepressants are rarely utilized due to adverse cardiac events.

Primary Palliative Care in Heart Failure and Indications for Specialty and Hospice Referral

Due to the difficulties of prognostication in heart failure, it has been recommended that palliative care approaches and specialty referral be symptom-centered rather than prognosis-driven.[54] In a recent randomized controlled trial of interdisciplinary palliative care plus usual care versus usual care alone,[55] hospitalized heart failure patients with high risk of mortality and rehospitalization were recruited. The investigators found improvements in QOL, anxiety, depression, and spiritual well-being favoring the intervention group, suggesting that prognosis-type factors may be useful indicators for specialty referral.

In the United States, hospice services are eligible under Medicare funding and most private insurer coverage if a patient with heart failure is deemed by two physicians or one physician and one nurse practitioner to have an estimated prognosis of 6 months or less, and the patient is willing to forego curative-intent therapies. Guidelines stipulate that patients have NYHA Class IV heart failure and are either (a) optimally treated with medications or (b) experiencing angina at rest despite nitrate therapy and have been deemed ineligible or have opted out of invasive cardiac procedures. Other supporting indications for hospice include left ventricular ejection fraction of 20% or less, treatment-resistant symptomatic arrhythmias, concomitant acquired immunodeficiency syndrome, and histories of cardiac syncope, embolism, and resuscitation.

End of Life Care

Advance Care Planning

To optimize shared decision-making, the ACC/AHA encourage an "annual heart failure review" where discussions about current and potential therapies and anticipated and unanticipated events can be discussed.[12] To this end, a discussion about one's goals of care and assessing understanding of the disease process is necessary to determine what the optimal future care plan should be. Because many patients lose their ability to make their wishes known during a serious, life-threatening event of illness, strong consideration to create an advance directive or living will is encouraged.[12] Critics of advance directive documents have noted that these documents are not effective in allowing sufficient control over future events; however, the process of advance care planning is more about devising a strategy to approach the anticipated and unanticipated events by best understanding patients' goals, values, and preferences.[56] Given the complexity of some life-sustaining therapies used in heart failure, it is encouraged that wishes about management of treatments like MCSDs should be explored proactively.[35] However, work to date has suggested that patients with implanted devices rarely have advance directives, and, of those that do have a directive and concurrently have an ICD,[57] pacemaker,[58] LVAD,[59] or TAH,[60] such directives rarely address how to manage the device as end of life approaches.

Withdrawal of Life-Sustaining Therapies

It is generally accepted that patients (or their surrogates, if the patient is not able) have the right to refuse unwanted medical treatments, even if such refusal results in one's death. While patients may opt to forego ICDs, pacemakers, or MCSDs, some may opt to receive these therapies with the hopes of achieving specific life goals such as prolonged survival or ability to complete important life work. If the treatment is no longer effective, it is legally and ethically acceptable that the treatment be discontinued, and this discontinuation does not constitute physician aid in dying, manslaughter, or suicide.[61] Patients will succumb to the underlying cause of the disease process (i.e., advanced heart failure) whether the treatment is never started, or discontinued at a later point. However, it is important to recognize that the discontinuation of life-sustaining treatment and resulting death may emotionally feel different for providers, patients, and surrogates alike.[61,62] Careful discussion of how the life-sustaining treatment will be handled in the future is encouraged at the time of implantation and iteratively as goals of care evolve. Box 47.1 describes steps clinicians should be aware of when deactivating LVADs.

Box 47.1. Important Steps and Pointers for Left Ventricular Assist Device (LVAD) Deactivation

Prior to Deactivation

1. Inform key members of the healthcare team, including (but not limited to): physician of record, cardiologist, cardiothoracic surgeon, LVAD coordinator, bedside nurse, unit nurse manager, palliative care consultant, social worker, chaplain, and ethics consultant (if needed).
2. Confirm and document the presence of advance directives, do-not-resuscitate orders, and designated healthcare proxy or durable power of attorney for healthcare.
3. Confirm and document the treatment plan goals and the content of any family meetings.
4. Discuss with patients and families, noting (a) any ethical concerns; (b) the process for deactivation, including the unpredictable timing of death after deactivation (minutes to short days); (c) who would like to be present at the time of deactivation; (d) what religious preferences or rites the patient or family would like to have recognized and/or performed; and (e) decisions that may need to be made after death such as organ donation, autopsy, and funeral arrangements.
5. After eliciting patient and families values and goals of care, make direct recommendations about other treatments besides the LVAD that should be stopped (e.g., mechanical ventilation, defibrillator) to align with those values and goals.
6. Discuss goals of comfort during and after LVAD deactivation and what treatments will be offered to meet those goals. Reassure the patient and family that patients can be kept comfortable without life-sustaining treatment.
7. Set the date and time for LVAD deactivation, assuring appropriate resources are present.

During Deactivation

1. LVAD deactivation is similar in many respects to mechanical ventilator withdrawal. Clinicians should be prepared to treat the rapid onset of dyspnea/labored respirations, agitation, and other signs of discomfort.
2. Check that all family members who expressed a desire to be with the patient during deactivation and that all appropriate healthcare staff are present.
3. Discontinue all monitoring that is not symptom-directed.
4. There are many different LVAD models with different steps to deactivation. Be familiar and review the specific steps to deactivate the device before performing the task in front of patients and families (especially alarm silencing, which can be distressing to patients and families). Consult your institution's LVAD coordinator as needed.
5. Once the LVAD is deactivated, cardiovascular circulation may greatly diminish. Thus, it is strongly encouraged to bolus with appropriate medications such as morphine for pain and dyspnea, lorazepam for agitation, and glycopyrrolate for secretions *prior* to deactivation and prior to withdrawal of other life-sustaining therapies. Have additional medication drawn up and ready to administer after deactivation if needed.

(*continued*)

Box 47.1. Continued

6. Once any post-LVAD deactivation symptoms have been appropriately managed, proceed with withdrawal of other life-sustaining treatments.
7. Monitor carefully for any signs of distress or discomfort, treat accordingly, and educate those present as needed regarding signs and symptoms observed.

After Deactivation and Death

1. Spend time with the family to discuss any concerns or questions.
2. After death occurs, encourage the family to spend as much time at the bedside as they desire.
3. Provide acute grief support and follow-up bereavement support.

Case Study: A Patient with Heart Failure

Charles Bennett, a 57-year-old man, presents to clinic for progressive dyspnea, a 3-lb weight gain over the past week, and depressed mood. Point of care BNP is greater than 150 pg/dL (normal value: <100 pg/dL). He has a past medical history of hypertension, myocardial infarction (2013, multivessel disease with coronary artery bypass grafting × 3), type II diabetes (A1c 7.3%), and a history of generalized anxiety disorder. He was diagnosed with progressive systolic dysfunction 4 years ago and has been followed by a cardiologist. At the time of diagnosis, Mr. Bennett worked as a plant manager at a local lime refinery, a physically demanding job with daily exposure to high kiln temperatures. He often oversaw student engineers during their internship experiences and regaled them with stories of kiln malfunctions and 20-hour days. Over the past 4 years, as his LVEF decreased from 40% to 20%, he could not keep up with the physical demands of his job and retired early from the company he had been with for more than 30 years. He was hospitalized 5 months ago with acute, decompensated heart failure and started home milrinone infusions. At a prior follow-up where his prognosis was discussed, his primary caregiver, his wife of 32 years, frequently brought up discontinuing the infusion. Upon further questioning by the nurse, the caregiver disclosed her growing discomfort with handling her husband's complex medical needs and Mr. Bennett's desire to remain at home due to "all these tubes." At that appointment, Mr. Bennett also added that he had nowhere he was supposed to go and affirmed feelings of depression. He was treated with an SSRI. Although his mood improved as noted during the assessment, Mr. Bennett still expressed sadness and frustration over his fluctuating functional status, his unexpected retirement, and his medication regimen, growing more frustrated by the noticeable breathlessness during conversation. Picking up on the discordance between the treatment plan and patient's desires, the nurse practitioner questioned Mr. Bennett about his understanding of his illness and disease trajectory as well as his care preferences. While Mr. Bennett understood that heart failure was a serious diagnosis, he felt sure that he could continue to be "tuned up." The nurse practitioner queried about Mr. Bennett's preferences regarding the milrinone and other therapies, and they discussed other potential treatments for his heart failure. Guided by the nurse practitioner, Mr. Bennett expressed some goals of care, including a desire to take less medicine and visit friends. Plans were made to discuss possible titration of milrinone with Mr. Bennett's cardiologist, and Mr. Bennett was connected to the heart failure support group sponsored by the local hospital.

Conclusion

Providing palliative care for patients with heart failure may start at the time of diagnosis concurrent with traditional treatment, marked by periods of increased utilization during acute exacerbations. Given the high prevalence of comorbidities in heart failure patients as well as the rise in first-time heart failure diagnosis in the elderly population, the focus of supportive care in heart failure is improved QOL, self-care, symptom management, care coordination, prognosis understanding, and decision-making. Despite poor functional status and significant symptom burden, including frequent emotional symptoms (of anxiety and depression), patients with advanced heart failure are often referred to palliative care services late or are resistant to palliative approaches due to optimal treatment response during exacerbations and unpredictable disease trajectory. Yet the burden of heart failure is ripe for palliative approaches by informed nurses guided by recent evidence-based practice guidelines. Relying on symptoms, not prognosis, might result in greater uptake of specialty palliative services, especially in the outpatient setting. While pharmacological and nonpharmacological therapies may be used to address common symptoms of breathlessness, pain, fatigue, and depression, goals of care discussions support the patient and their caregivers (or support persons) during medical decisions such as heart transplantation, mechanical circulatory support devices, or home inotrope infusion considerations. Palliative care addresses the multifaceted burden of those living with heart failure, whether through symptom management or advance care planning, with improved QOL and relief of suffering a priority and with nurses at the forefront.

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SECTION V

End-of-Life Care across Settings

CHAPTER 48

Improving the Quality of Care across All Settings

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and James T. McDaniel

Key Points

- Quality palliative care is a result of intelligent systematic efforts to raise standards of care throughout an organization.
- Tools are available to assist in the monitoring and measurement of structure, process, and competency in the delivery of palliative care.
- Outcome measures are needed to evaluate the impact of innovative change on patient and family quality of life, healthcare systems, and professional practice.

Quality Improvement and End-of-Life Care Defined

The term quality improvement (QI) is now commonplace in the lexicon of industry and government healthcare systems in the United States. In this chapter, QI in healthcare is defined generically as the philosophy driving a systematic approach to improving clinical practice processes and patient outcomes, systems, education, and research. End-of-life (EOL) care refers to care received in the final hours or days of life and includes care to patients and families living with a terminal illness or condition that has become advanced, progressive, and incurable. Quality palliative and EOL care is a result of intelligent systematic efforts to raise standards of care throughout an organization.

The Need for Better Palliative Care and End-of-Life Care in the United States

The World Health Organization defines palliative care as "the active total care of patients whose disease is not responsive to curative treatment when control of pain, of other symptoms and of psychological, social and spiritual problems is paramount."[1] Palliative care is often referred to as supportive care or comfort care that seeks to prevent, relieve, alleviate, lessen, or soothe the symptoms of disease without effecting a cure. The Institute of Medicine's (IOM) landmark report in 1997, *Approaching Death: Improving Care at End of Life*, informed the field about areas most deficient and those of highest priority for improvement. In the decade following the report, professional and national associations addressed the priorities, including the need for a synthesis of the state-of-the-knowledge in EOL care, evaluation methods for measuring outcomes, factors impeding high-quality care, and steps toward agreement on what constitutes "appropriate care" at the end of life.[2] The IOM report includes results from the national SUPPORT study, which produced more than 104 publications supporting the deficiencies in care and citing the frequency of aggressive medical treatment at the end of life (deaths occurring in the intensive care unit [ICU]) and the lack of adequate symptom management (conscious patients with moderate to severe pain).

Since the IOM report, national and professional organizations and field experts have been addressing these gaps in knowledge and the need for better symptom management and more awareness by professionals of patient preferences for care at the end of life. For example, the Agency for Healthcare Research and Quality'(AHRQ) sponsors technical evidence panels (TEP) and, with the National Institutes of Health, offers national symposiums to provide updates in the field about quality indicators and areas of greatest need. Research efforts to address the deficiencies in EOL care are increasing; however, little progress has been made in standardizing the assessment of the delivery of quality care and quality outcome indicators.

Most quality professionals agree that "If it can be measured, it can be managed." Hence the search for the best quality indicators. A 2007 systematic review revealed psychometrically sound measures of outcomes in EOL care and results of interventions. Of 24,423 citations reviewed, 99 measures met criteria for inclusion. Of these 99, 35 measures were recommended in a prior systematic review, and 64 measures of the EOL care experience were added by the reviewers. They found the most robust measures in the areas of symptoms, quality of life (QOL), and satisfaction, with significant gaps existing in continuity of care, advance care planning, spirituality, and caregiver well-being. The authors call for more rigorous development and testing of measures and for designs that facilitate comparability across care settings, populations, and clinical conditions.[3]

The cost of providing EOL care has become an important area of study in the United States as we move away from fee-for-service reimbursement structures to capitation models whereby a fixed amount of money is given per patient per unit. In one report, palliative care experts urge hospital executives to pay attention to the

5% of patients who are driving 50% of their spending budgets. They insist that this 5% group is the growing number of over-85 elders—expected to reach 8.5 million by 2030. They estimate that 27% of Medicare dollars are spent on the last year of life when most of these elders will spend some time in the hospital. The report emphasizes the need to manage this 5% of the population well and to encourage better access to palliative care.[4]

Palliative care increases patient and family satisfaction and quality of care and supports better bedside care and resource allocation.[5] The number of US hospitals with palliative care programs tripled over the past decade, with US registries in 2016 showing that 90% percent of hospitals with 300 beds or more had a palliative care program. Hospitals face the pressures of Medicare's value-based purchasing programs, which require use of quality metrics and patient and family satisfaction measures. Further support for the positive outcomes of palliative care programs is found in a recent study of heart failure patients who were randomized to usual care plus palliative care versus usual care alone over a 6-month period. Those advanced heart failure patients receiving an interdisciplinary palliative care intervention showed consistently greater benefits in QOL, anxiety, depression, and spiritual well-being compared with usual care alone.[6]

Early EOL care discussions are prospectively associated with less aggressive care and greater use of hospice at end of life. In one retrospective study of 6,122 decedents over a decade, an upward trend was seen in the proportion of elderly (>60 year) with an advance directive, an increase from 47% in 2000 to 72% in 2010. Patients who had EOL care discussions with their physicians before the last 30 days of life were less likely to receive aggressive measures at end of life, including chemotherapy ($P = .003$), acute care ($P < .001$), or any aggressive care ($P < .001$). Such patients were also more likely to receive hospice care ($P < .001$) and to have hospice initiated earlier ($P < .001$).[7] In another study of 332 advanced cancer patients followed until death (for nearly 5 months), only 37% reported having had an advance care planning discussion with their physician.[8]

National- and state-level initiatives are increasing the quality and frequency of discussions and completion of advance directives. For example, in 2012, the Institute for Healthcare Improvement (IHI) in collaboration with The Conversation Project, launched a public engagement campaign to encourage people to "have the conversation" about their wishes for EOL care with loved ones, with the goal that everyone's wishes are expressed and respected. The Conversation Project has received national attention for its starter toolkits in various languages and educational webinars addressing the barriers to having conversation for professionals, patients, and families. For more information, visit http://www.ihi.org/Engage/Initiatives/ConversationProject/Pages/default.aspx.

Quality Principles Spread from the Car Industry to Healthcare

Nearly a century ago, W. Edwards Deming, the American engineer who assisted Japan in its quest for quality after World War II, continues to influence healthcare organizations.[9] His QI principles and methods for systematic and statistical thinking are being woven into the fabric of everyday work life. It is important for clinicians to understand the history behind the quality movement from countries like Japan and the car industry and their influence on today's US healthcare culture.

Mastering the concepts and tools of QI is critical to building a skill-set for the improvement process. The tools we still use today date back to 1920, nearly a century ago, and were developed by pioneers such as Deming, Juran, Shewhart, Ishikawa, and Pareto. These tools are described in the following paragraphs.

IHI, LEAN, and Six Sigma

The IHI, led by Don Berwick, was the first organization to adopt Deming's teachings and work with US healthcare organizations to "fix broken systems" that were creating poor-quality and unsafe care, such as high medication error rates in hospitals. Known as the Triple Aim, IHI engaged healthcare organizations in the largest effort to improve the experience of care and the health of populations and to reduce national per capita costs. The Triple Aim has recently been called the Quadruple aim, to include improved clinician experience and the work life of healthcare providers.

Another quality framework is the Lean and Six Sigma's 7-Step Problem-Solving Method. John Krafcik coined the term "lean" as an approach aimed at improving efficiency by removing waste. In his study of Japanese car companies, he observed that Toyota did "everything with half of everything": half the people, half the space, half the inventory, half the resources, yet with very high quality. The ground-breaking book, *The Machine that Changed the World* (1990), with its focus on the automotive sector, was the origin of lean thinking and made a compelling case for its adoption in any industry.

LEAN Six Sigma, a popular framework driving change today in healthcare, focuses on reducing error or defects, as measured by a *sigma level*. The sigma level or how much the process varies from perfection, is measured as the number of "defects per million opportunities." Three standard deviations above and below the mean create the upper and lower control limits of the six sigma framework by following six basic steps, known as DMAIC: *define* the problem in detail, *measure* defects (in terms of "defects per million," or sigma level), *analyze* in depth using process measures and tools such as flow charts and defect analysis to determine under what conditions errors or defects occur, *improve* by defining and testing changes aimed at reducing defects, and *control* by defining what steps will be taken to maintain performance.

In their book *Lean Thinking* (1996), authors distill Lean into five principles: (1) specify the value desired by the customer, (2) identify the value stream for each product providing that value and challenge all of the wasted steps (generally nine out of ten) currently necessary to provide it, (3) make the product flow continuously through the remaining value-added steps, (4) introduce pull between all steps where continuous flow is possible, and (5) manage toward perfection so that the number of steps and the amount of time and information needed to serve the customer continually falls.

By the 1990s, Lean thinking and Six Sigma techniques spread to US healthcare when the Healthcare Reform Act of 1992 challenged all agencies to adopt QI methods to achieve better control over inconsistencies and waste in services. Training is easily accessible for those interested in QI. With the help of web-based learning systems, virtual teams of professionals are offering mentorship and resources in international, national, and regional collaborative efforts to improve care around specific content areas. For more readings and online courses in QI visit http://www.shmula.com and https://www.lean.org/WhatsLean/ and http://www.ihi.org and https://www.villanovau.com.

The important point here is not which framework you choose; rather it's choosing the one that works for you in your setting and helps to improve outcomes of care and how it is delivered. Four tools and their inventors are presented next because they are fundamental to all frameworks previously reviewed and are key in understanding how systematic and statistical thinking promote quality and making improvements. The *Pareto Principle* (aka, *80:20 rule*) implies that 80% of any problem is accounted for by 20% of the contributing factors. It is wiser to concentrate on the "vital few" rather than the trivial many. Figure 48.1 shows a Pareto chart. Clinicians are deciding where to target their efforts next to reduce patients' episodes of sustained pain. The second tool is Shewhart's four-step management method, *plan–do–study–act* (PDSA). Also called the *Deming wheel*, it is used to study a problem in quality control. An example of results of a repeated PDSA cycle are displayed in a control chart. Figure 48.2 features one hospital unit's stability on one patient satisfaction item asking patients how well staff were managing their pain. The third concept, created by Joseph Juran, stressed the "costs" of poor quality, such as wasted effort, extra expense, and increase in defects (or errors). Juran's manufacturing techniques are fundamental to the quality *lean thinking movement* of today. The fourth tool is the *Ishikawa fishbone diagram* or *cause-and-effect diagram*. Fishbones display specific root causes of an event, and the sources of the error are commonly grouped into five categories: Machine (equipment, technology), Method (process), Material (includes raw material, consumables, and information), Man/mind power (physical or knowledge work), and Measurement/medium (inspection, environment). See a sample fishbone diagram in Appendix 48.1.

Federal and Professional Groups Adopt Standards and Metrics Across Settings to Evaluate Quality End-of-Life Care

A seminal document for palliative care professionals is the guidelines published by the National Consensus Project for Quality Palliative Care.[10] These clinical practice guidelines, based on both available scientific evidence and expert professional opinion, have become the accepted means of promoting consistency, comprehensiveness, and quality across eight domains of healthcare: structure and processes of care; physical, psychological, social, spiritual, cultural, ethical and legal aspects of care; and care of the imminently dying. Guidelines that cross all domains include assessment, information sharing, decision-making, care planning, and care delivery at the end of life. Adoption of these guidelines in the United States will help to promote high-quality care to persons living with life-threatening and debilitating chronic illness. In 2006, another seminal document, the *National Framework and Preferred Practices for Palliative and Hospice Care Quality*, endorsed by the National Quality Forum (NQF), serves as a foundation on which quality measurement and reporting systems are currently being built. The most recent 2015–2016 Palliative and End-of-Life Standing Committee 2015–2016 endorsed 23 measures to improve palliative and hospice care.[11]

The Centers for Medicare and Medicaid Services (CMS) has taken the lead in setting quality outcome measures at the end of life across settings. CMS Certified hospices deliver approximately 45% of the nation's EOL care and are the focal point for measuring the overall value of the federal benefit offered to those meeting eligibility in the last 6 months of life. In August 2017, CMS unveiled the Hospice Compare website, posting seven quality measures that allow consumers to compare hospices on their performance

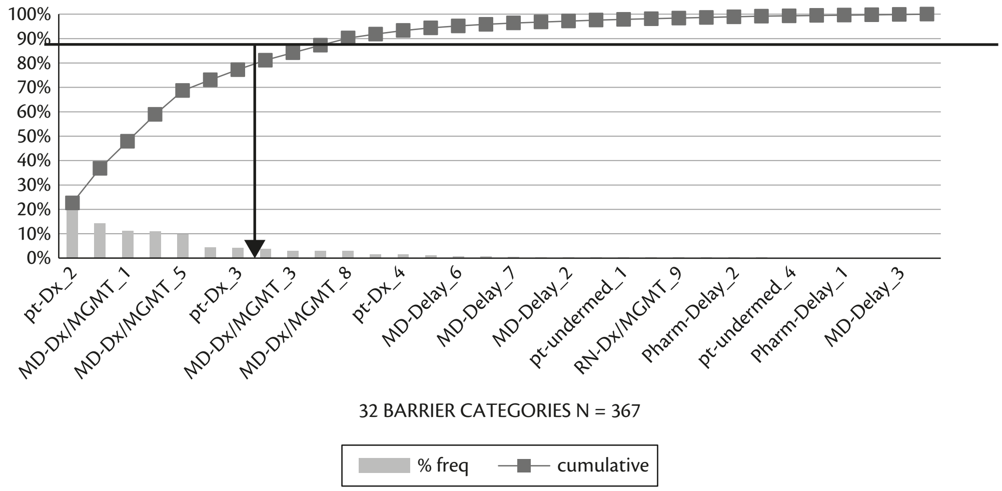


Figure 48.1 The Pareto Chart. *Problem/Issue*: The NP of a medical unit was charged with improving communication between the pain specialists and hospitalists to identify the factors that were contributing to patients with sustained pain (i.e., pain scores of 5 or greater [0, no pain, 10 worst pain] over 2 consecutive days). *Methods*: Data were collected on 367 patients, including their demographics and clinicians' suspected reasons for the unrelieved pain. The NP used a Pareto Chart to display the data about possible barriers creating the most resistance to improved pain management. A frequency distribution of the 32 barriers documented was sorted (high to low), and the top 20% (7 barriers) were uncovered. These 20% were contributing to 80% of the problem. These included the patient's specific pain diagnoses. *Outcome*: The most frequent diagnoses included sickle cell disease (pt-Dx_2) and chronic pain (pt-Dx_3). They were identified as the top diagnoses for patient admissions through the emergency room (ER), followed by the treatment they received (MD-DX/MGMT_1 and MD-DX/MGMT_3), which were not adequate to relieve the sustained high pain scores. Specific care plans were developed to meet this population's pain needs. *Action plan*: The pain specialist and hospitalist teams created a pathway for both patient groups as they entered the ER including a prompt call to pain specialists and a pathway with standing orders for admission.

Source: https://betterexplained.com/articles/understanding-the-pareto-principle-the-8020-rule/

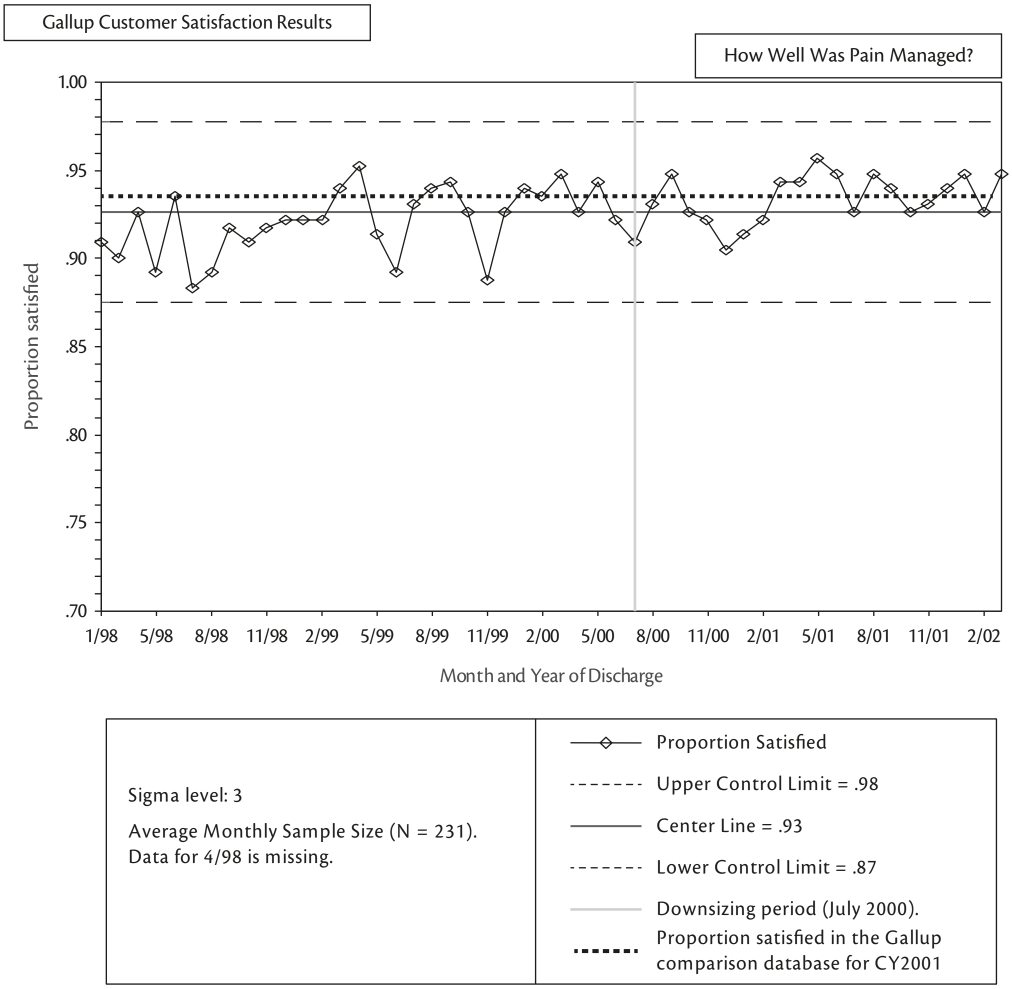


Figure 48.2 A control chart showing statistical control and stability of a process: managing pain.
Problem/Issue: A clinical nurse specialist (CNS) from pain management services has patient satisfaction data spanning several years. She has prepared a control chart with results of one question in the survey "How well was your pain managed?" She plans to showcase the good work by the oncology unit staff and demonstrate a process that is in control. *Methods*: By plotting the satisfaction scores and creating upper and lower control limits (3 standard deviations from the mean), the CNS teaches the value of displaying data and how to look for common and special causes of variation. She uses the "rule of seven tests" to interpret the control chart and look for special causes (along with points beyond the limits). The tests reflect an out-of-control situation in the data: (1) seven points in a row above the average, (2) seven points in a row below the average, (3) seven points in a row trending up, or (4) seven points in a row trending down (a string of seven low or seven high scores indicates the need to look further and seek reasons for the pattern). *Outcome*: The CNS illustrated with a control chart that the pain management process was within statistical control. Patients reported high levels of satisfaction over a sustained period.

Source: https://www.isixsigma.com/tools-templates/control-charts/a-guide-to-control-charts/; https://www.spcforexcel.com/knowledge/control-charts-basics/interpreting-control-charts#rule-of-seven-tests; and http://www.au.af.mil/au/awc/awcgate/navy/bpi_manual/mod10-control.pdf

and assist them in making decisions about where to receive care. The Hospice Item Set (HIS) used in Hospice Compare was chosen from the National Quality Forum (NQF). The standardized 7-item set is intended to capture patient-level data on each hospice patient admission: patient preferences, beliefs and values, pain assessment and screening, dyspnea screening and treatment, and if bowel regimens are in place for patients receiving opioids.[12]

In addition to evaluating the quality of care being delivered, hospices are required to evaluate quality care using post-death family satisfaction surveys: the Consumer Assessment of Healthcare Providers & Systems (CAHPS) Hospice Survey instrument evaluates the following categories: hospice team communication, getting timely care, treating family member with respect, getting emotional and religious support, getting help for symptoms, getting hospice care training, rating of hospice, and willingness to recommend the hospice.[13]

Long-term care, skilled nursing facilities, and rehabilitation centers are also required to collect data on the quality of care delivered for each resident in a Medicare- or Medicaid-certified nursing home. Data are obtained at admission, quarterly, annually, and whenever the resident experiences a significant change in status. Known as the Minimum Data Set (MDS), information is collected on the resident's health, physical functioning, mental status, and general well-being. These data are used by the facility to assess the needs of and develop a plan of care unique to each resident. On September 18, 2014, Congress passed the Improving Medicare Post-Acute Care Transformation Act of 2014 (the IMPACT Act). The Act requires the submission of standardized data by long-term care hospitals, skilled nursing facilities, home health agencies, and inpatient rehabilitation facilities.[14]

The IMPACT Act requires the reporting of standardized patient assessment data with regard to quality measures, resource use, and other measures. Data collected across settings will support the exchange of data among various providers using common standards and definitions. This effort will provide access to longitudinal information for providers and facilitate coordinated care and improved Medicare beneficiary outcomes.

In 2018, hospital and community settings will publicly report their outcomes on patient and family satisfaction with care during and after episodes of care.

Other CMS quality initiatives around EOL care include improving transitions between care settings, preventing medical errors, preventing unnecessary hospitalizations and readmissions, support for consumers' preferences and choices, and avoiding duplication of services. For more information about other CMS initiatives, visit https://www.medicaid.gov/medicaid/quality-of-care/improvement-initiatives/care-transitions/index.html.

The American Academy of Hospice and Palliative Medicine (AAHPM) and the Hospice and Palliative Nurses Association (HPNA) has launched the "Measuring What Matters" campaign with 10 performance measures for all hospice and palliative care programs to use for improvement. The 10 quality indicators shown in Box 48.1 could eventually enable benchmarking in the field.[15]

Box 48.1 Ten Quality Indicators for Seriously Ill, Palliative Care, and Hospice Patients

1. A comprehensive assessment (physical, psychological, social, spiritual, and functional) soon after admission
2. Screened for pain, shortness of breath, nausea, and constipation during the admission visit
3. If screen positive for at least moderate pain, receive treatment (medication or other) within 24 hours
4. Documented discussion regarding emotional needs
5. Documentation of the surrogate decision-maker's name and contact information or absence of a surrogate
6. Documentation of their preferences for life-sustaining treatments
7. Patients or their families are asked about their experience of care using a relevant survey
8. Hospice patients have a documented discussion of spiritual concerns or preference not to discuss them
9. Patients with advanced or life-threatening illness are screened for shortness of breath and, if positive to at least a moderate degree, have a plan to manage it
10. Vulnerable elders with documented preferences to withhold or withdraw life-sustaining treatments have their preferences followed

Source: Adapted from The American Academy of Hospice and Palliative Medicine (AAHPM) and the Hospice and Palliative Nurses Association (HPNA) Measuring What Matters. Available at http://aahpm.org/quality/measuring-what-matters

Application of the FOCUS_PDSA Model to Improve End-of-Life Care

QI experts agree that "quality is never an accident" and that it is "always the result of intelligent effort, intent, and vigilance to make a superior thing." To achieve this, QI teams need a systematic methodology to follow. In the following study, a multidisciplinary QI team applied Deming's six key principles of QI and the FOCUS-PDSA model to improve inpatient EOL care in a large New York City hospital. The case describes a 1-year study led by palliative care experts on three pilot units: oncology, geriatrics, and hospice. Two medical units—intensive care and step-down—served as control units. A Palliative Care for Advanced Disease (PCAD) pathway for care of the imminently dying inpatient was developed and tested. Table 48.1 illustrates Deming's six principles applied to the PCAD QI Study.[16]

We illustrate the process with the PCAD Pathway team's application of each step in the QI rapid cycle (see Appendix 48A.1). The PDCA (plan–do–check–act) is also commonly known as the PDSA cycle.[9] The FOCUS part of the model is aimed at team-building, clarifying the nature and scope of the improvement needed, exploring innovative interventions through literature and experts to reduce variation in care, finding measures for evaluation, and gathering information about the culture and setting where the study will be done.

Focus

- *Find a process to improve*. The process to study was delivery of EOL care to imminently dying inpatients on the five hospital units known to have the highest volume of patient deaths. Chart reviews of patient deaths investigated 2 years earlier identified a need.
- *Organize to improve a process.* A 28-member QI team of stakeholders spanned departments and disciplines to address EOL care issues such as ethics, social work, chaplains, pharmacists, nurses, and physicians. Pain and palliative care experts took the lead.
- *Clarify what is known.* Flowcharts were created to map the ideal process of care and increase dialogue among the team's disciplines about "why" EOL care varied. The team regrouped into four concurrent subcommittees: (1) care-path development, (2) implementation, (3) education, and (4) evaluation, including searches of internal and external sources of evidence and rationale in EOL care.
- *Understand variation.* Brainstorming helped the team elicit reasons for variations in the care process and identify potential barriers. An Ishikawa diagram (to display cause and effect) was used to show the barriers related to materials, methods, people, and equipment. All subcommittees considered the barriers when planning and implementing the program.
- *Select a process improvement.* The four subcommittees developed evidence-based interventions: the three-part PCAD care path (a multidisciplinary care path, a flow sheet for daily documentation of care, and a physician's order sheet that includes suggested medications for treating 15 of the most prevalent symptoms at EOL care); nurse, physician, other staff, patient, and family educational materials; a timeline and detailed plan for implementation, education, and evaluation of PCAD; and tools to measure professional, patient and family, and system outcomes. Goals of the PCAD care path are listed in Box 48.2.

Table 48.1 Deming's quality principle and application to the PCAD pathway pilot project

Principle	Discussion	Application
1. Customer-driven	The focus is on customers, both internal and external, and understanding them. Teams strive to achieve products/services to better meet needs and exceed expectations of customers.	Chart reviews of patient deaths reveal areas to improve: Documentation regarding advance directive discussions, symptom management effectiveness, spiritual and psychosocial care, treatment decisions in last 48 hours of life. Focus groups with caregivers reveal need for better communication with health professionals about patient's progress.
2. System optimization and alignment	Organizations/teams are systems of interdependent parts, with the same mission and goals for customers.	Hospital-wide multidisciplinary continuous quality improvement (CQI) team is formed to reduce variation in EOL care with three standardized tools that provide guidelines for care (care path), documentation, and physician orders.
	Optimizing performance of the entire system means aligning the processes, technology, people, values, and policies to support team efforts to continually improve.	Ongoing resources from Pain and Palliative Care available to pilot unit staff (one advanced practice nurse).
3. Continual improvement and innovation	Focus shifts to processes of care and using a systematic and scientific approach. Methods seek to reduce and control unnecessary process variation and improve outcomes.	Flowcharting and brainstorming techniques help identify current activities and unit norms for EOL care regarding establishing goals of care, advance directives, respecting patient and family preferences, and barriers to implementing goals of project.
4. Continual learning	Resources are available to develop a culture in which people seek to learn from each other and access new sources of evidence. Feedback mechanisms support the use of evidence to drive improvements	Extensive literature searches and team expertise guide development of clinical tools and educational materials. Team members receive education regarding issues in EOL care, viewing of Education in Palliative and EOL Care (EPEC, ELNEC). Adult learning principles guide sequencing and content of educational session for unit staff (e.g., physiology of dying).
5. Management through knowledge	Decision-making is based on knowledge, confirmed with facts about what is "best practice," and guided by statistical thinking.	Team uses FOCUS-PDSA methodology to structure study processes. Content experts in EOL care, measurement, outcomes, and QI guide sampling, selected outcome measures, and graphic display of data.
6. Collaboration and mutual respect	Organizations/teams engage everyone in the process of improvement and in the discovery of new knowledge and innovations. Mutual respect for the dignity, knowledge, and potential, contributions of others is valued by members.	Team forms subcommittees to develop materials in these areas based on expertise and interest: Care-path development, flow sheet, physicians' orders. Implementation (timeline for phases of planning, launching, rollout, evaluation, dissemination, and decisions to adopt practice changes). Education (staff, patient, and family). Outcomes (patient, family, staff knowledge, process audit of new tools).

EOL, end-of-life.

Box 48.2 Goals of the Palliative Care for Advanced Disease Pathway

- Respect patient autonomy, values, and decisions.
- Continually clarify goals of care.
- Minimize symptom distress at the end of life.
- Optimize appropriate supportive interventions and consultations.
- Reduce unnecessary interventions.
- Support families by coordinating services.
- Eliminate unnecessary regulations.
- Provide bereavement services for families and staff.
- Facilitate the transition to alternate care settings, such as hospice, when appropriate.

The PDSA Cycle: Plan–Do–Study–Act

Also known as the *Shewhart cycle*, PDSA rapid-cycles are the evaluation aspect of the study and its iterative problem-solving process. The next step is to test the change in the real work setting. The PDSA cycle is shorthand for testing a change—planning it, trying it, observing the results, and acting on what is learned. Similar to an audit and feedback approach, the user is given results about the new intervention, and, if goals are not met, users provide feedback and the intervention is either changed and tested or remains the same. This is the scientific method, using action-oriented learning. We explain the PDSA cycle using the education subcommittee's goal to achieve a greater than 90% total score on the Palliative Care Quiz for Nurses with all nursing staff.

- *Plan*. In this step, a timeline of activities for the 1-year pilot prepared administration, team members, and others with direction, goals, and resources. The sample timeline in Figure 48A.5 illustrates the various phases involved in launching the pilot

Table 48.2 Principles for assuring the quality of data

Principle	Key point
Validity/reliability	There is accuracy and consistency in data collection.
Completeness	Measurement system includes a policy for missing data and timeliness of collection.
Sampling method	Sample size is determined by power analysis to ensure representativeness of population.
Outlier cases	Measurement systems make efforts to validate or correct outliers.
Data specification	There are standardized definitions and terminology for transmission/use of data across departments.
Internal standards	Prespecified data-quality standards are tailored for individual performance measures.
External standards	There is a commitment to implementing data sets, codes, and methodologies developed by accrediting bodies (e.g., government, professional organizations) for data use across healthcare systems.
Auditability	Data are traceable to the individual case level.
Monitoring process	Ongoing data-measurement process in place is based on prespecified standards.
Documentation	Data standards and findings are recorded and available for review.
Feedback	Performance systems regularly provide summary reports on data quality to organization leadership.
Education	Performance systems provide support through education, on-site visits, and guidelines to ensure quality data.
Accountability	Measurement systems are responsible for data quality and dissemination to participating members.

project: the planning phase; rollout or introduction phase; and the implementation, evaluation, and dissemination, and reporting phases. Then the study design is crafted. This includes determination of sample size and selection, what data will be collected and by whom, what tools will be used and when they will be applied, what training will be conducted and by whom, and who will perform data analysis. Table 48.2 outlines principles for assuring the quality of data.

- *Do*. Baseline measures are obtained, interventions are implemented, and data collection begins. In the PCAD study, several premeasures were obtained, including baseline knowledge using Ross's Palliative Care Quiz for Nurses,[17] chart reviews, and focus groups with staff.
- *Check/Study*. The results of data collection are checked and analyzed by the team and the next steps formulated. The audit and feedback loop of discussions ensues again. For example, the EOL care group used the findings from the knowledge pretest to identify areas for continuing education. Through consensus, members agreed that knowledge items answered incorrectly by 15% of staff would be targeted for continued education.

Measures and Repeated Use of the Cycle

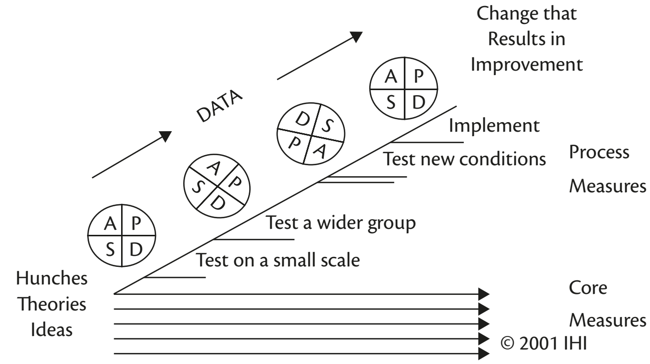


Figure 48.3 General approach to sequential plan–do–study–act (PDSA) cycles.
Source: Institute for Healthcare Improvement (IHI).

- *Act*. Action plans are developed, including a timeline and those accountable for completion. The study team gave monthly feedback to the QI team, pilot units, and the hospital QI department quarterly. Knowledge scores on pilot units were lowest on items about the dying process. Staff requested specific education in "the physiology of dying." Palliative care experts gave education to all staff on the intervention floors. Knowledge tests were repeated at 3- and 6-month intervals to identify additional gaps in understanding palliative care and EOL care.

Measures and Repeated Use of the Cycle

Figure 48.3 shows the general approach to sequential PDSA cycles. Teams are encouraged to make small changes rapidly and, once goals are met, to repeat the PDSA cycle with the next phase of the process or move to another process. Unlike an experimental research protocol, teams are encouraged to make changes in the intervention at each cycle test if they don't reach their targets. The tweaking of the new change, based on feedback from front-line users, encourages innovation and engagement. Encouraging teams to reach their targeted goals quickly reinforces team-building and motivates the teams to examine other processes. More detailed readings on the rapid cycle testing are available at http://www.ihi.org/resources/Pages/HowtoImprove/default.aspx.

The audit and feedback approach has shown positive outcomes. A Cochrane systematic review of 140 studies shows that audit and feedback interventions generally lead to small but potentially important improvements in professional behaviors and patient outcomes. In this process, an individual's professional practice or performance is reviewed against a standard or target, and then results are given back to the individual. The aim of the process is to encourage the individual to follow professional standards.[18]

Developing Key Performance Indicators to Improve End-of-Life Care

The next segment gives the reader strategies for improving quality palliative care and EOL care using Donabedian's classic structure, process, and outcome framework.[19] Table 48.3 presents selected

Table 48.3 Quality measures and references for improving end-of-life care across settings

Author(s)	End-of-life care measures	Target audience	Source
American Academy of Hospice and Palliative care	10 Performance Measures 12 quality measures by eight domains	Hospice benchmarks	Available at http://aahpm.org/quality/measuring-what-matters Available at http://aahpm.org/uploads/education/MWM%20Top%2012%20Measure%20Information%20and%20Comments.pdf
CAHPS Hospice	47 items in 9 categories of satisfaction	Hospice family of deceased	Available at *http://www.hospicecahpssurvey.org/*
De Roo, M (2014)	326 Quality Indicators by 8 domains of palliative care	International and all settings	De Roo ML, Leemans K, Claessen SJJ, Cohen J, Pasman HRW, Deliens L, Francke AL. Quality indicators for palliative care: update of a systematic review. *J Pain Symp Manage* 2013;46(4):556–572.
HCAHPS	9 categories of quality measures of satisfaction	Hospital inpatient experience	Available at http://www.hcahpsonline.org/home.aspx
Hospice Compare (CMS)	7 Indicators	Hospice documentation	Available at https://www.medicare.gov/hospicecompare
National Hospice and Palliative Care	6 Performance Measures	Hospice benchmarks	Available at http://www.nhpco.org/performancemeasures
The Joint Commission (TJC) Advanced Certification in Palliative Care	Standards	Hospital	Available at https://www.jointcommission.org/facts_about_palliative_care/
TJC Community-Based Palliative Care Certification	Standards	Home-Based Agency	Available at https://www.jointcommission.org/accreditation/home_care_accreditation.aspx
Twaddle et al. (2007)	11 Key performance measures	Hospital benchmarks for palliative care programs	Twaddle ML, et al. Benchmarks from academic medical centers. *J Palliat Med* 2007;86–88.
National Quality Forum	38 Preferred Practices	Palliative care professionals	Available at https://www.qualityforum.org/Publications/2006/12/A_National_Framework_and_Preferred_Practices_for_Palliative_and_Hospice_Care_Quality.aspx
PEACE	23 Quality Measures	Hospice	Available at http://www.med.unc.edu/pcare/files/assessment-instruments-for-end-of-life-care Available at http://aahpm.org/uploads/education/MWM%20Top%2012%20Measure%20Information%20and%20Comments.pdf
Teno, J	8 domains of quality EOL care	After death interview—family of deceased	Teno J. Time: Toolkit of Instruments to Measure End-of-Life Care [accessed on August 6, 2005]. Center for Gerontology and Healthcare Research, Brown Medical School. Available at thttp://www.chcr.brown.edu/pcoc/toolkit.htm.
Quality of Dying and Death (QODD)	Domain(s): Quality of Care -multidimensional Life, Functional Status, Advance Care Planning, Spirituality, Grief and Bereavement, Caregiver Well-Being	Inpatient ICU Unique surveys for professionals, patients, and families	Curtis JR, Patrick DL, Engelberg RA, et al. 2002. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. *J Pain Sympt Manage* 2002;24(1):17–31. Mularski RA, Curtis JR, Osborne ML, Engelberg RA, Ganzini L. Agreement among family members in their assessment of the quality of dying and death. *J Pain Sympt Manage* 2004;28(4):306–315. Available at http://depts.washington.edu/eolcare/products/instruments/

priority measures and tools for professionals performing QI in and across settings in EOL care.

Structure

Standards of Care Provide Structure

The beacon of quality standards in US healthcare remains The Joint Commission (TJC), a nonprofit organization which accredits and certifies more than 20,000 healthcare organizations and programs in the United States to meet certain performance standards, including EOL care. TJC has led the nation with standards for quality care in palliative care and EOL care in hospitals and the community: the Advanced Certification Program for Palliative Care, launched in 2011, has certified 90 US hospital programs as of 2017.[20] In July 2016, TJC launched a Certification Program for Community-Based

Palliative Care and has certified 21 US home-based agencies.[21] The certification status is designed to recognize programs that demonstrate exceptional patient- and family-centered care that aims to optimize the QOL for patients with serious illnesses.

In QI, the term "benchmark" is used to refer to "the search for the best practices that consistently produce best-in-the-world results"—the gold standard. QI teams are increasingly joining benchmarking associations, such as the Association for Benchmarking Healthcare and the Six Sigma Healthcare Benchmarking Association that offer mentorship, education, newsletters, and participation in benchmarking studies relevant to healthcare needs.[22,23] Clinicians seeking to make improvements in the appropriateness, effectiveness, and cost-effectiveness of care can look to their national and specialty organizations for standards, guidelines, position papers, and research models for EOL care.[24,25] Guidelines can describe appropriate management of specific symptoms and provide a basis for assessment, treatment, and outcomes. When the evidence is weak, as is the case for much of EOL care, guidelines or standards need to be supported with recommendations made through expert consensus. Standards, policies, procedures, and assessment tools for palliative care clinicians can be found at the Center to Advance Palliative Care (CAPC), whose website is updated frequently. Its intent is to assist programs in implementing quality palliative care in accordance with TJC standards. The documents can be accessed at www.capc.org.

Process

Process refers to the series of linked (but not necessarily sequential) steps that, by design, deliver a set of results. Answering the question "What are the key processes for delivering 'best practices' to a dying patient?" can generate many work flows and ideas for QI. QI operates on the principle that people do their best but are constrained by systems and processes that need to be addressed. Nurses' routine processes include screening, assessment, diagnosis, reassessment, treatment, evaluation, and documentation of patient care: all critical to producing positive patient and family outcomes. Assessment and reassessment of symptoms such as pain, dyspnea, agitation, delirium, nausea, diarrhea, and constipation are important processes leading to nursing interventions that can reduce the suffering of dying patients.

As clinicians have been challenged to deliver high-quality care at lower cost, there has been an explosion of tools developed to reduce variability in the processes of care. *Algorithms* and *clinical pathways* and *protocols* are three such tools that offer streamlined workflows for teams to monitor and manage the processes of patient care. These tools define desired patient outcomes for specific medical conditions and delineate the optimal sequence and timing of interventions to be performed by professionals. Those interested in adopting validated assessment tools for EOL care are referred to the PEACE Project sponsored by the Carolinas Center for Medical Excellence (CCME) and the University of North Carolina-Chapel Hill, under contract with CMS. Twenty-two hospices participated in a national Quality Improvement Collaborative (QIC) to pilot-test the usability and feasibility of potential quality measures and data collection processes for hospice and palliative care programs. The 23 quality measures for EOL care are organized into eight domains and described at http://www.med.unc.edu/pcare/files/assessment-instruments-for-end-of-life-care.

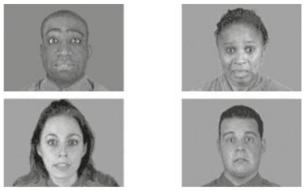
Algorithms and Standardized Orders Streamline Processes

Algorithms are step-by-step guides for clinicians to use in their day-to-day work. Figure 48.4 shows an example of a simple tool

Respiratory Distress Observation Scale © (Margaret L. Campbell, PhD, RN 2/19/09)

Variable	0 points	1 point	2 points	Total
Heart rate per minute	<90 beats	90-109 beats	≥110 beats	
Respiratory rate per minute	≤18 breaths	19-30 breaths	>30 breaths	
Restlessness: non-purposeful movements	None	Occasional, slight movements	Frequent movements	
Paradoxical breathing pattern: abdomen moves in on inspiration	None		Present	
Accessory muscle use: rise in clavicle during inspiration	None	Slight rise	Pronounced rise	
Grunting at end-expiration: guttural sound	None		Present	
Nasal flaring: involuntary movement of nares	None		Present	
Look of fear	None		Eyes wide open, facial muscles tense, brow furrowed, mouth open, teeth together	
Total				

1. RDOS is not a substitute for patient self-report if able.
2. RDOS is an adult assessment tool.
3. RDOS cannot be used when the patient is paralyzed with a neuromuscular blocking agent.
4. RDOS is not valid in bulbar ALS or quadriplegia.
5. Count respiratory and heart rates for one-minute; auscultate if necessary.
6. Grunting may be audible with intubated patients on auscultation.
7. Fearful facial expressions:



Source: Campbell (2010), reference 29.

Figure 48.4 The Respiratory Distress Observational Scale (RDOS).
Source: Reference 26. Used with permission.

to measure respiratory distress developed by a leading nurse researcher in critical care, palliative care, and EOL care, Dr. Margaret Campbell.[26] The tool offers clinicians a validated method for assessing and monitoring one of the three most distressing symptoms for patients and their families at end of life: pain, dyspnea and agitation. Nurses are encouraged to build validated tools into their daily practice protocols, which include treatment options of pharmacological and nonpharmacological interventions.[27]

Clinical Pathways and Protocols Reduce Variation in Processes of Care

The term "pathway" refers to clinical trails that form a structured, multidisciplinary action plan. It defines the key events, activities, and expected outcomes of care for each discipline during each day of care. Pathways are evidence-driven, reflect best practices, and delineate the optimal sequence and timing of interventions. The goal of using a pathway is to "reduce variation in services and practices, thus reducing costs and negative patient outcomes."[16,28] Box 48.3 shows a six-step process for developing pathways. Box 48.4 lists commonly used elements of care and interventions. Reducing variation in any process (clinical decision-making or care delivery) takes three steps. The first step is to study the process as it currently operates (usually done through flowcharting and brainstorming) to identify potential sources of variation and to learn about which activities are likely to achieve the desirable outcomes. The second step is to stabilize the process by getting everyone to use the same procedures, equipment, and materials, and still recognize the need for individualized patient care. This is usually done by repeated audit and feedback of results to users, educating about procedures, and involving users in tweaking the process and in individual responses. The third step is to measure again and again and repeat the process until control within agreed-upon limits is reached. Standardizing care, however, should never compromise an individual's care needs.

Outcomes

Outcome measures evaluate the impact of innovative change on patient and family QOL, healthcare systems, and professional practice. Outcomes are the results of actions or nonaction to structures, processes, patients and caregivers, professionals, and systems in the organization. Examples of outcomes include reduced symptom distress, improved family satisfaction, improved perceived support of professional caregivers, and reduced costs of EOL care.

Clinicians will need to become proficient at measuring the outcomes of their care. Federal and state governments, private purchasers, physicians, nurses, insurers, labor unions, health plans, hospitals, and accreditation organizations, among others, have placed pressure on organizations to address some of the significant quality problems in US healthcare systems (http://www.ahcpr.gov/qual).[29,30] The Centers of Medicare and Medicaid Services' pay-for-performance initiative is designed to support better quality care of Medicare beneficiaries. About 100 such initiatives are in progress across the country. The general intent is to reward hospitals and doctors for providing better care. We will need to improve our ability to measure and report the quality of care being delivered. Such reporting prompts a closer look at provider and healthcare practices, both as feedback for clinicians and as publicly available score cards for consumer evaluation.

Measuring Patient, Family, and Clinician Satisfaction with End-of-Life Care

"Achieving and producing health and satisfaction, is the ultimate validator of the quality of care."[19] There has been limited research in examining satisfaction among terminally ill and dying patients and families and yet, for most dying patients, satisfaction may be the most important outcome variable for themselves and their families, notes Professor Irene J. Higginson, an international leading researcher for more than two decades. She has been using the audit cycle and feedback process to improve outcomes in palliative care and notes the difficulties in obtaining outcome information—such as QOL—from the weakest group of patients. She supports the need to test the use of proxies to obtain this important information. The Palliative Outcome Scale is one such tool that is used by many clinicians in palliative care in a variety of settings to measure physical and psychological symptoms, spiritual considerations, practical concerns, and psychosocial needs. Readers seeking measures to be used in clinical audits are referred to the work of Dr. Higginson.[31]

The quality of care provided to dying patients is being obtained through after-death interviews of families. One such tool, the Family Assessment of Treatment at the End of Life Short Form (FATE-S)[32]

Box 48.3 The Six-Step Process to Developing a Care Path

1. Identify high-volume, high-priority case types, review medical records, review and evaluate current literature to characterize the specific problems, average length of stay, critical events, and practical outcomes.
2. Write the critical path, a flow chart defining the sequence and timing of functions to be performed by physicians, nurses, and other staff.
3. Have nurses, physicians, and other disciplines involved in the process review the plan of care.
4. Revise the pathway until consensus on care components is reached.
5. Pilot-test the pathway and revise as needed.
6. Incorporate pathway patient management into quality improvement programs, which include monitoring and evaluating patient care outcomes.

Box 48.4 Routine Elements of a Care Path

- Physical elements
- Medications
- Nutrition and dietary
- Vital signs, intake and output, weight
- Comfort assessment
- Safety and activity
- Diagnostic lab work
- Intravenous use
- Transfusions
- Diagnostic tests
- Psychosocial and spiritual needs
- Referrals and consultations
- Patient and family counseling and education

is routinely used in the Veterans Administration (VA) system in at least 70 hospitals and 60 nursing homes. The validated tool has 14 items, including one global rating, and assesses the domains of communication, treatment preferences, dignity, spiritual support, psychosocial support, pain control, planning for death, and overall care to patient.

Another widely used tool in commonwealth nations is FAMCARE. Based on qualitative research methods, family members are asked to list the indicators of quality of palliative care from the patient's and their own perspective.[33]

Obtaining the perspective of clinicians caring for patients and families at end of life offers another view on the quality of care given to the imminently dying. Figure 48.5 presents a new validated audit tool for conducting an EOL care Tracer that can guide assessment and rate care when used to evaluate the quality of care for the dying inpatient. *Tracers* are used by TJC surveyors to evaluate whether standards of care are being followed. Before reviewing a patient's record for the presence of quality care, they might interview the nurse caring for the patient, the doctor, a social worker, and a chaplain, in addition to interviewing the patient and/or family members about their satisfaction with care.

The EOL care Tracer began with an initial pool of 248 items to evaluate overall quality in eight specific content areas of palliative care (e.g., symptom management). Collected into three instruments,

Tracer EoLC v1

Conducting the Review: **Date:**

Please rate the quality of care that the patient and family received during the 48 hours before the patient died. Base your ratings on personal observations, the medical record, and interviews. Mark "NA" if you are unable to evaluate the care.

		N/A	Poor	Fair	Good	Very Good	Excellent
Care of the Patient							
1.	Overall, how would you rate the quality of care the patient received for symptom control?						
2.	Overall, how would you rate the quality of care the patient received to address goals of care discussions?						
3.	Overall, how would you rate the quality of care the patient received to address religious and/or spiritual concerns?						
4.	Overall, how would you rate the quality of care the patient received to address psychosocial concerns?						
5.	Overall, how would you rate the quality of care the patient received during the last hours before death?						
6.	How would you rate the overall care the patient received during the last 48h of life?						
Care of the Family							
7.	Overall, how would you rate the quality of care the family received to address communication concerns?						
8.	Overall, how would you rate the quality of care the family received to address goals of care discussions?						
9.	Overall, how would you rate the quality of care the family received to address advance care planning issues?						
10.	Overall, how would you rate the quality of care the family received to address traditions and customs?						
11.	Overall, how would you rate the quality of care the family received to address religious and/or spiritual concerns?						
12.	Overall, how would you rate the quality of care the family received during the patient's last hours before death?						
13.	Overall, how would you rate the quality of care the family received after the patient's death occurred?						
14.	How would you rate the overall care the family received during the patient's last 48h of life?						

Probe items to consider in completing Tracer EoLC-v1

Figure 48.5 Tracer end-of-life care V1.

Source: Reference 35.

1. Symptom Control for moderate to severe symptom distress

- ☐ Repeated assessments conducted?
- ☐ Medication given around the clock?
- ☐ Reassessments indicating relief?
- ☐ Additional action taken if symptoms not relieved/reduced?

2. Communication (among patient and family and whole team)

- ☐ Opportunities to communicate with patient and/or family?
- ☐ Interpreter sought for language barriers answered by medical team?
- ☐ Patient and family supported?
- ☐ Care consistent with patient and family concerns?

3. Goals of care and advance care planning

- ☐ Goals of care discussed with patient and/or family?
- ☐ Care consistent with goals of care?
- ☐ Attempts to avoid/reduce invasive tests and procedures?
- ☐ Advance directives: Planning for future medical care
  - ○ Surrogate decision maker identified (or attempt made)?
  - ○ Resuscitation orders clear?
  - ○ Care consistent with patient advance care directives?

4. Traditions and customs

- ☐ Care adequately addressed language difficulties, family involvement, respect for elders, decision-maker, deference to authority of doctor
- ☐ Patient's environment appropriately adjusted to meet preferences (noise, odor, light, private room, family space, special cultural items allowed)?
- ☐ Specific care-related traditions, customs or way of life supported?

5. Religious and/or spiritual care

- ☐ Religious/spiritual needs appropriately assessed and efforts made to support those needs?
- ☐ Preferences related to post mortem care identified?
- ☐ Access to acceptable chaplain/pastoral care?
- ☐ Access to religious rituals appropriate to beliefs?

6. Psychosocial care

- ☐ Psychosocial assessment of patient and family conducted?
- ☐ Efforts made to meet psychosocial needs?
- ☐ Family given opportunity to be present during dying period?
- ☐ Family supported during dying phase?
- ☐ Bereavement needs addressed?
- ☐ Family identified if high risk for complicated grieving?

7. Last hours

- ☐ Environment adjusted to meet patient/family preferences?
- ☐ Environment adjusted to support dignity of patient and family during dying phase?
- ☐ Patients personal hygiene attended to (e.g., mouth, eyes, wounds)?
- ☐ Patient and family treated with respect?
- ☐ Family given appropriate, timely and empathic information about death when it occurred?

8. After the death

- ☐ Dignity of the deceased preserved (traditions and customs upheld re: post mortem care/ funeral plans)?
- ☐ Family given appropriate, timely and empathic information about what would happen to body upon leaving unit?

With permission from Bookbinder, M et al, (in press) Development and Field-Test of a Tool and Methodology for a Self-Assessment Tracer to Evaluate the Quality of End-of-Life Care, *J Pain Symptom Manage*: 2017, Elsevier, 2017.

Figure 48.5 Continued

the items were used to interview professional caregivers and evaluate the charts of hospitalized patients who died. Evidence that this information could be validly captured using a small number of items was obtained through factor analyses, canonical correlations, and group comparisons. Chart reviews of 145 deaths and data from 445 professional interviews (26 physicians, 108 nurses, 18 social workers, and 9 chaplains) about care given in the last 48 hours of life yielded the 14-item Tracer EOL care v1 shown in Figure 48.5.[34, 35]

The United States participates in international research on EOL care. The Quality of Death Index Ranking in palliative care ranks palliative care and EOL care experiences across the world. In 2015, the United States ranked 9 out of 80 countries providing data on 20 indicators across five categories: the palliative and healthcare environment, human resources, the affordability of care, the quality of care, and the level of community engagement.[36]

Process Indicators

These indicators measure a specific aspect of nursing practice that is related to flow of work: flow of information, materials, or patient care. Examples of process indicators might include pain screening, assessments, implementation of an intervention, reassessment, prompt management of complications, and documentation. These indicators describe "how care is to be delivered and recorded." Sometimes it may be difficult to separate process indicators from outcome indicators. For example, if an improvement study is directed toward reducing discomfort related to dyspnea in dying patients, then the indicator might involve the process of assessment of respirations, obtaining an order, and giving appropriate medication within a designated time period. The indicator might read that 100% of patients with severe dyspnea will be assessed and treated with appropriate medications within a 2-hour period. Another segment of the same process may produce an indicator that reads that 100% of patients treated for severe dyspnea will achieve relief (reduction to mild dyspnea) within 8 hours.

INDICATOR: Number of patients with severe dyspnea reaching mild dyspnea within 8 hours/The total number of patients experiencing severe dyspnea (designated period)

Low results on this indicator might prompt a special QI team to investigate the barriers to reaching the goal of the indicator. The team may learn that the dyspnea measure is too difficult to administer, too time-consuming, or too confusing to assess mild, moderate, and severe dyspnea. Is the computer screen's field for documenting care not easy to use? Were physician's orders not appropriate for treating severe dyspnea? Were calls made to providers with delays in answering? Any of these pieces of the process could trigger a new look at the process of reaching mild relief of this symptom, including testing the use of a dyspnea algorithm.

Quality Improvement Indicators: Measuring Organizational Performance

A *clinical indicator*, also called a *key performance indicator* (KPI), is typically defined as a quantitative measure that evaluates the quality of important patient care and support-service activities. Indicators that directly affect quality services typically include such factors as timeliness, efficiency, appropriateness, accessibility, continuity, privacy and confidentiality, comfort, participation of patients and families, and safety and supportiveness of the care environment. Although they are not direct measures of quality, indicators serve as "screens" or "flags" that direct attention to specific performance areas that should be targets for ongoing investigation within an organization.

Institutions surveyed by TJC in the past two decades have experienced the shift in focus of performance from competence and skills ("Is the organization able to provide quality services?") to productivity and outcomes ("To what extent does the organization provide quality services?") and efficiency ("To what extent does the organization use resources efficiently?"). For example, rather than requesting a review of the institution's policy and procedure manual for a pain or palliative care program, surveyors might evaluate whether pain standards have been implemented and to what extent relief was obtained and the patients' satisfaction with care and their understanding of side effects associated with analgesics. The "tracer" methodology is standard procedure for TJC surveyors. Nurses and other clinicians will need to be knowledgeable in this area as the accreditation process promises to become more rigorous in areas affecting our largest and most costly group of citizens: the ill elderly.

Indicators can reflect a performance measure such as competence or safety. *Competence* means that individuals or the organization have the ability (e.g., education, behavioral skills) to provide quality services; *safety* means that those abilities are translated into actions that achieve quality outcomes without untoward effects. Results of indicators can reveal deviations from the norm and may warn of impending problems. Indicators may require a single-item measure, multiple items, or multiple tools. Indicators are typically expressed as an event or ratio (percentage). Examples of structure, process, and outcome indicators that are clinical (patient care), professional (competence), and administrative (satisfaction) are described here.

Structural Indicators

These are derived from standards of care and need to be aligned with the mission, philosophy, goals, and policies of the organization (e.g., community agency, hospital, department, or unit). Structure standards measure whether the authorized norms in the field are being followed. For example, a standard and its accompanying policy may read that all (100%) patients admitted to the hospital or hospice require discussion and documentation about advance directives within 48 hours of admission. The percentage obtained would indicate the extent to which adherence to the 100% goal is being met. A structural indicator on an oncology unit might read:

INDICATOR: Number of records with documentation of a discussion of advance directives/Total number of patients who were admitted to the oncology unit (determined period)

Staff competence is another structural indicator. This indicator may reflect a standard and policy that requires all geriatric unit staff pass a competency in EOL care. The competency might consist of written exam (cognitive) and demonstration of skill (behavioral) in the use of an EOL care pathway (see Figure 48A.5 for a sample knowledge quiz in palliative care). For this indicator, a threshold is determined for successful completion, such as 90% on the written exam plus three return demonstrations in the use of the pathway. Low results on this indicator might suggest the need to send key staff to an EOL care training for nurses such as the End-of-Life Nursing Education Consortium (ELNEC). Readers can visit http://www.aacn.nche.edu/ELNEC/ to read more about ELNEC's national effort and courses available.

Outcome Indicators

These indicators measure what does or does not happen after something is or is not done. Most organizations have shifted their focus from examining the documentation of processes of care to measuring outcomes of care and learning which treatment works best, under what conditions, by which individuals, and at what cost. Examples of outcome indicators for quality EOL care include family

Box 48.5 Areas for Improving Quality Care at the End-of-Life

- Physical and emotional symptoms
- Support of function and autonomy
- Advance care planning, including goals of care discussions
- Aggressive care near death, including preferences about site of death, CPR, hospitalization, nutrition, and hydration
- Patient and family satisfaction
- Religious and spiritual and cultural preferences
- Global quality of life
- Caregiver burden (family and professionals)
- Survival time
- Provider continuity, competency, and skill
- Transitions in care settings
- Bereavement services

satisfaction with care (family), symptom control (patient), respect for patient cultural and religious preferences, family support and communication at the time of the patient's death, and referral for ethics consultation if no healthcare agent is identified. Outcome indicators such as these might be appropriate following the implementation of a multidisciplinary pathway to improve care of dying inpatients. The goal might be to achieve a family satisfaction with care rating of 90% very satisfied, using a 0–5 scale (0 = very dissatisfied to 5 = very satisfied). An oncology unit might decide that designated family members will be contacted at 3 to 4 months following the patient's death for an interview about satisfaction with care.[34] The indicator would read: 90% of families will report being very satisfied with care when asked about overall satisfaction with the patient's care in the last days of life. In this example, the response rate from families should ideally be more than 50% so that findings are used with confidence and not viewed as biased.

INDICATOR: Number of families scoring very satisfied with overall care/Number of persons completing satisfaction surveys following the death of a family member (Designated Period)

See the preceding section on patient, family, and clinician satisfaction with EOL care for examples of outcome measures. Box 48.5 summarizes priority areas to improve quality care at the end of life.

Conclusion

Nurses, especially those in advance practice roles, are poised in pivotal roles across settings to improve the quality of care of the dying in the decades ahead. Our professional and advocacy organizations and the literature can lead us to which areas of EOL care are priorities for improvement. Many were outlined earlier. Advanced practice nurses need to have skill sets in quality improvement and in using research so that we can study with confidence "what works and what does not work" for patients and families and professional caregivers in our practice settings. We need to keep reading the literature, and we must stay active in developing and testing QI models, tools, and interventions toward better EOL care. We need to test interventions for improved symptom management, especially dyspnea and agitation; develop models for assuring "best practices" using research in vulnerable populations; and integrate QI methods into everyday palliative care practices. Palliative and EOL care is gradually being integrated into basic and advanced practice registered nursing (APRN) curricula, and the number of graduates from APRN fellowships[37] and externships[38] and doctoral programs in pain and palliative care centers of excellence is increasing, providing leadership in academic and clinical settings.[39-45] Nurses will need to strengthen their involvement in national and international efforts that educate professionals and consumers and influence healthcare policy in EOL care issues.

To survive, our healthcare systems must be able to change and improve rapidly. As with any other service operation, health systems require systematic innovation efforts to remain competitive, cost-efficient, and up to date. If the quality of EOL care is to improve, nurses will need to have expert knowledge about making change: how to encourage, measure, manage, and evaluate changes within and across organizations and settings. This knowledge needs to be coupled with the methods and know-how to produce change. Clinical audits and feedback are evidence-based strategies that are known to increase accountability and encourage dialogue among all ranks of staff, disciplines, and services. We will need to evaluate and compare EOL care across settings. Work is needed to develop standardized measures and definitions that are applicable to the setting and stage of illness while maintaining patient-centeredness. Nurses with expertise in quality and QI methods can provide the leadership needed to shape a practice culture that supports continuous testing of innovative strategies for improving care at the end of life.

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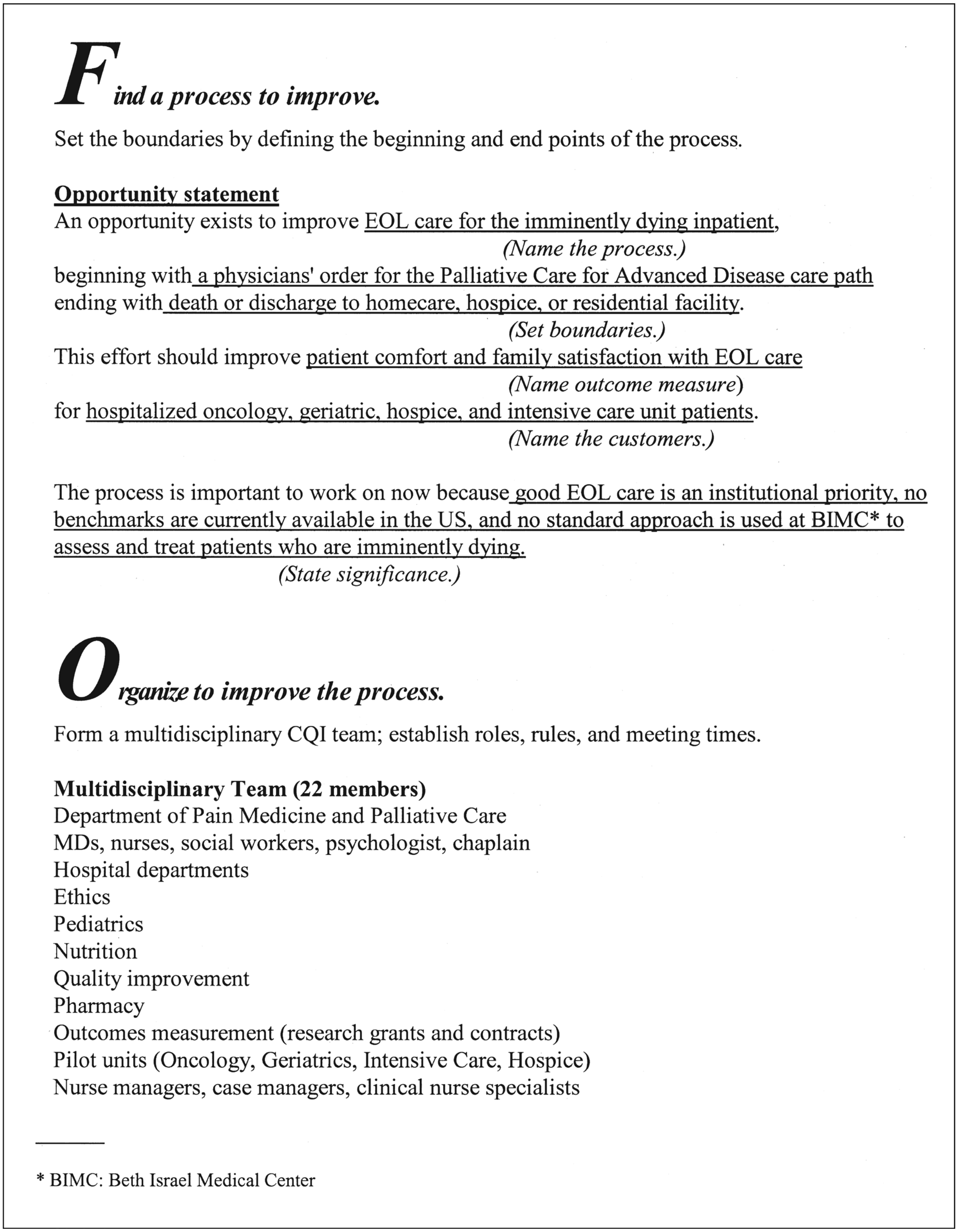
Appendix 48.1



Find a process to improve.

Set the boundaries by defining the beginning and end points of the process.

Opportunity statement

An opportunity exists to improve EOL care for the imminently dying inpatient,
(Name the process.)
beginning with a physicians' order for the Palliative Care for Advanced Disease care path
ending with death or discharge to homecare, hospice, or residential facility.
(Set boundaries.)
This effort should improve patient comfort and family satisfaction with EOL care
(Name outcome measure)
for hospitalized oncology, geriatric, hospice, and intensive care unit patients.
(Name the customers.)

The process is important to work on now because good EOL care is an institutional priority, no benchmarks are currently available in the US, and no standard approach is used at BIMC* to assess and treat patients who are imminently dying.
(State significance.)

Organize to improve the process.

Form a multidisciplinary CQI team; establish roles, rules, and meeting times.

Multidisciplinary Team (22 members)
Department of Pain Medicine and Palliative Care
MDs, nurses, social workers, psychologist, chaplain
Hospital departments
Ethics
Pediatrics
Nutrition
Quality improvement
Pharmacy
Outcomes measurement (research grants and contracts)
Pilot units (Oncology, Geriatrics, Intensive Care, Hospice)
Nurse managers, case managers, clinical nurse specialists

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* BIMC: Beth Israel Medical Center

Figure 48A.1 The FOCUS portion of the FOCUS-PDCA cycle.

Source: Continuum Health Partners, Inc., Beth Israel Medical Center, Department of Pain Medicine and Palliative Care, New York. Palliative Care for Advanced Disease (PCAD) Care Path; CQI Team on End-of-Life Care.

Clarify what is known.

FLOWCHART OF PALLIATIVE CARE FOR ADVANCED DISEASE (PCAD) CARE PATH

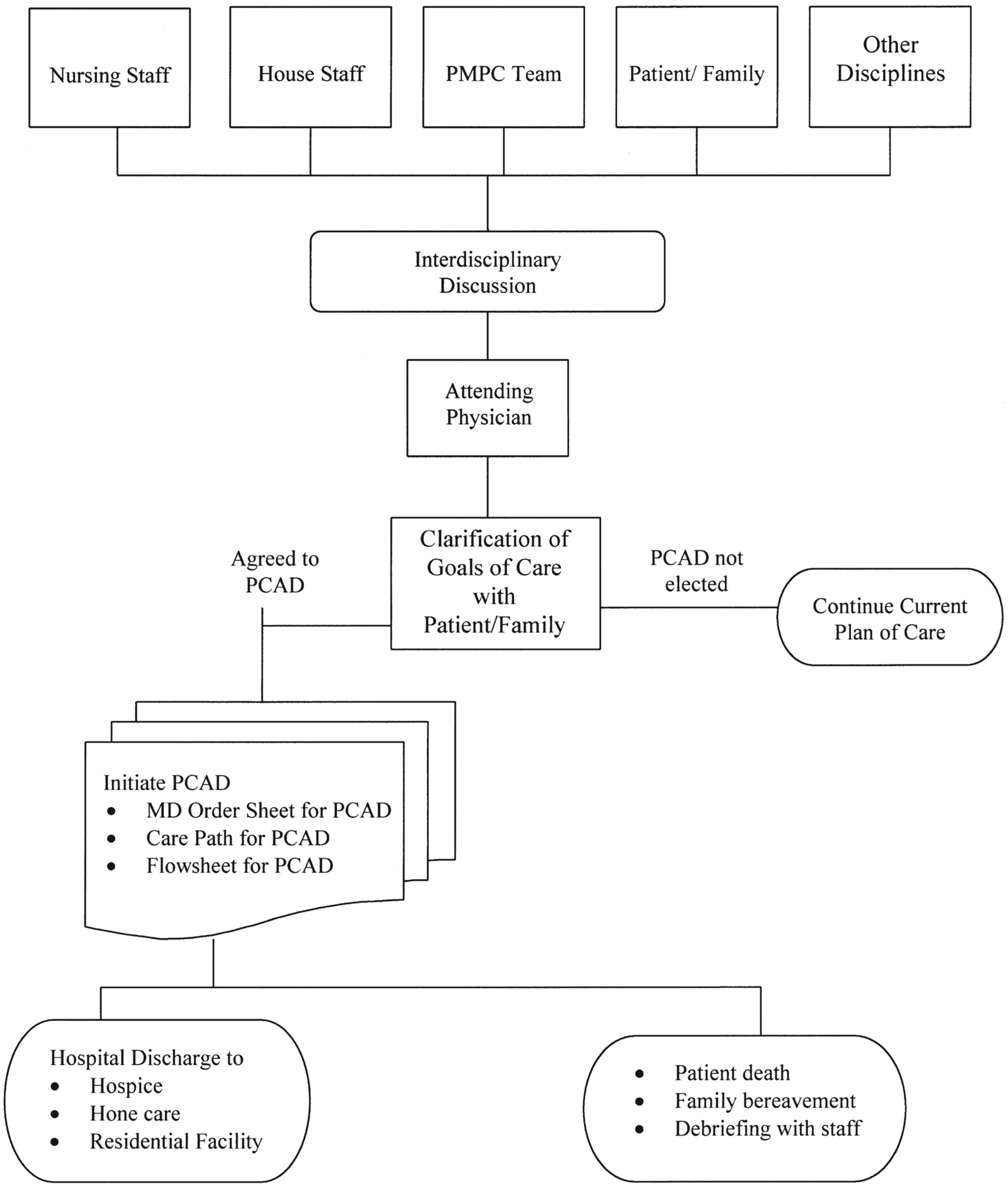

Nursing Staff
House Staff
PMPC Team
Patient/ Family
Other Disciplines
Interdisciplinary Discussion
Attending Physician
Clarification of Goals of Care with Patient/Family
Agreed to PCAD
PCAD not elected
Continue Current Plan of Care
Initiate PCAD
MD Order Sheet for PCAD
Care Path for PCAD
Flowsheet for PCAD
Hospital Discharge to
Hospice
Hone care
Residential Facility
Patient death
Family bereavement
Debriefing with staff

Figure 48A.1 Continued

Understand the variation

Brainstorm with those at the grass roots level about why the process varies. Categorize sources of variation by people, materials, methods, and equipment. Display data using a cause-and-effect diagram.

Brainstorming Session with CQI Team on End-of-life (EOL) Care Question:
What barriers could be encountered in implementing an EOL Pathway at BIMC?

EOL awareness/ discomfort/readiness:

- What is "end-of-life care?" When is treatment palliative vs. life ending? How do we choose?
- Patient, family, readiness/awareness of dying
- Physician, family, patient willingness to acknowledge that death is imminent
- Issues of truth telling: family may not know status of patient prior to the pathway
- Physician discomfort with stopping treatment
- Medical uncertainty about when to stop treatment

Team communication:

- Physician and nurse discomfort in discussing change in treatment strategy
- Is it the physician's decision alone? The heath care team as a whole needs to be acknowledged in decision.
- Definition of terms. Need to define who the team is. May need a new model.
- Nurses' comfort—may be put in the middle of team/family attending and decisions.

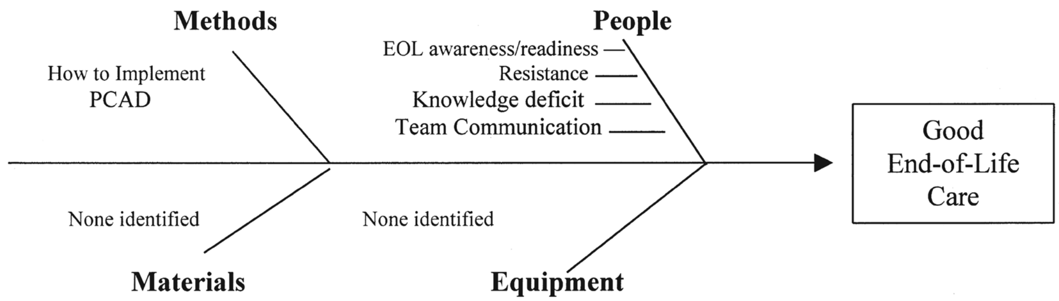
Unit resistance:

- Resistance of unit teams. May see this project as "another thing to do."
- Large-scale resistance. Some may not see that there is something to "fix."
- Organizational pressure to discharge quickly.

Knowledge deficit:

- Assumptions about pastoral care (patient, family, staff) and what the experience will be.
- Knowledge deficit about medical and nursing interventions
- How to implement the care path and encourage people to speak up front rather than later
- Large cultural diversity at BIMC
- Education needed about biomedical analysis and ethical problems
- Physician/patient and physician/family communication skills

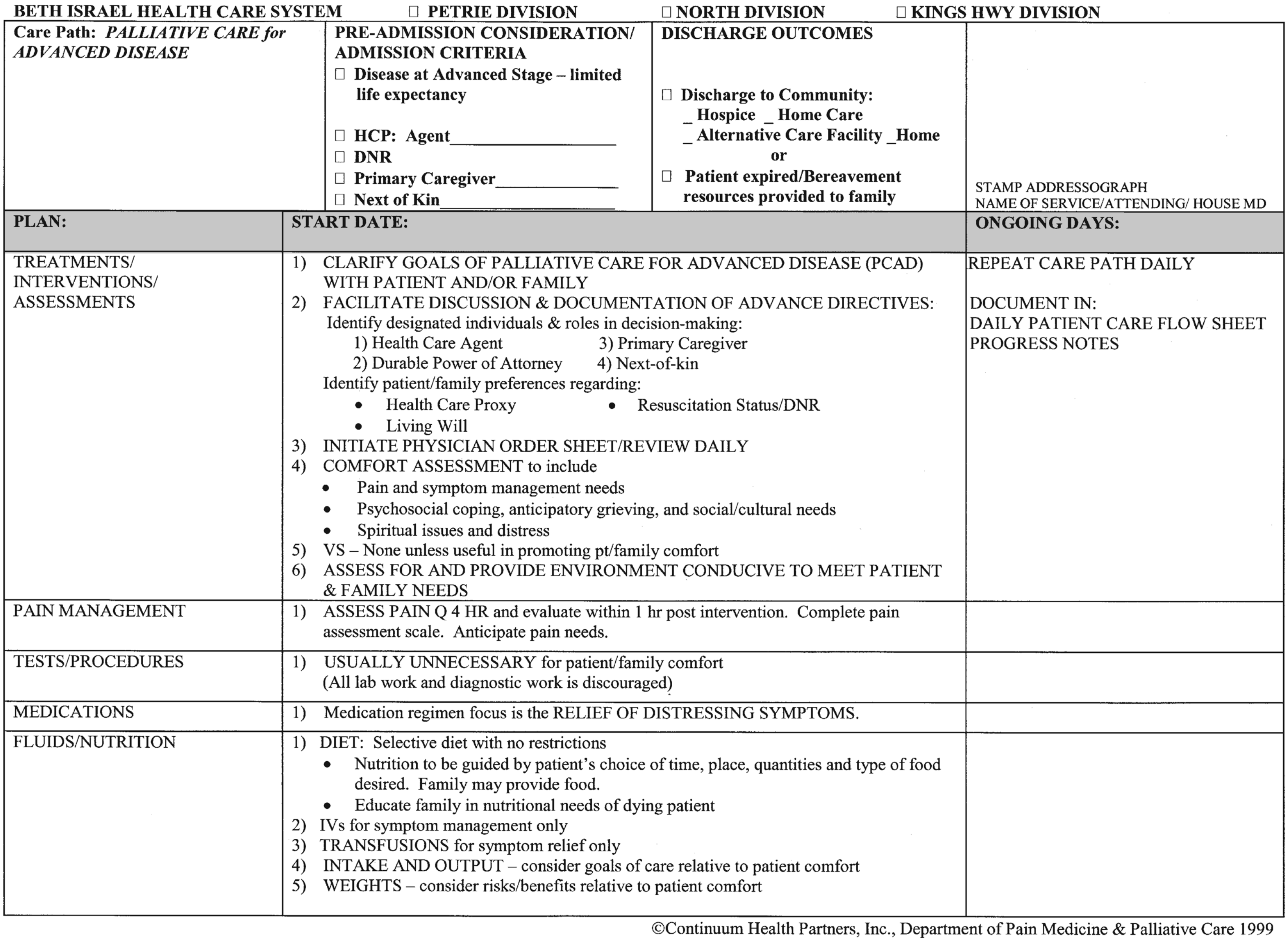
Cause and Effect (Ishikawa) Diagram (Barriers to implementing PCAD)—Themes above



Select the process improvement.

Describe the new intervention in detail. Palliative Care for Advanced Disease (PCAD) Care Path: Care Path, Flow Sheet, and Physicians' Order Sheet **(see following pages)**

Figure 48A.1 Continued



BETH ISRAEL HEALTH CARE SYSTEM ☐ **PETRIE DIVISION** ☐ **NORTH DIVISION** ☐ **KINGS HWY DIVISION**

Care Path: ***PALLIATIVE CARE for ADVANCED DISEASE***	**PRE-ADMISSION CONSIDERATION/ ADMISSION CRITERIA** ☐ **Disease at Advanced Stage – limited life expectancy** ☐ **HCP: Agent__________________** ☐ **DNR** ☐ **Primary Caregiver_____________** ☐ **Next of Kin__________________**	**DISCHARGE OUTCOMES** ☐ **Discharge to Community:** **_ Hospice _ Home Care** **_ Alternative Care Facility _Home** **or** ☐ **Patient expired/Bereavement resources provided to family**	STAMP ADDRESSOGRAPH NAME OF SERVICE/ATTENDING/ HOUSE MD

PLAN:	**START DATE:**	**ONGOING DAYS:**
TREATMENTS/ INTERVENTIONS/ ASSESSMENTS	1) CLARIFY GOALS OF PALLIATIVE CARE FOR ADVANCED DISEASE (PCAD) WITH PATIENT AND/OR FAMILY 2) FACILITATE DISCUSSION & DOCUMENTATION OF ADVANCE DIRECTIVES: Identify designated individuals & roles in decision-making: 1) Health Care Agent 3) Primary Caregiver 2) Durable Power of Attorney 4) Next-of-kin Identify patient/family preferences regarding: • Health Care Proxy • Resuscitation Status/DNR • Living Will 3) INITIATE PHYSICIAN ORDER SHEET/REVIEW DAILY 4) COMFORT ASSESSMENT to include • Pain and symptom management needs • Psychosocial coping, anticipatory grieving, and social/cultural needs • Spiritual issues and distress 5) VS – None unless useful in promoting pt/family comfort 6) ASSESS FOR AND PROVIDE ENVIRONMENT CONDUCIVE TO MEET PATIENT & FAMILY NEEDS	REPEAT CARE PATH DAILY DOCUMENT IN: DAILY PATIENT CARE FLOW SHEET PROGRESS NOTES
PAIN MANAGEMENT	1) ASSESS PAIN Q 4 HR and evaluate within 1 hr post intervention. Complete pain assessment scale. Anticipate pain needs.	
TESTS/PROCEDURES	1) USUALLY UNNECESSARY for patient/family comfort (All lab work and diagnostic work is discouraged)	
MEDICATIONS	1) Medication regimen focus is the RELIEF OF DISTRESSING SYMPTOMS.	
FLUIDS/NUTRITION	1) DIET: Selective diet with no restrictions • Nutrition to be guided by patient's choice of time, place, quantities and type of food desired. Family may provide food. • Educate family in nutritional needs of dying patient 2) IVs for symptom management only 3) TRANSFUSIONS for symptom relief only 4) INTAKE AND OUTPUT – consider goals of care relative to patient comfort 5) WEIGHTS – consider risks/benefits relative to patient comfort	

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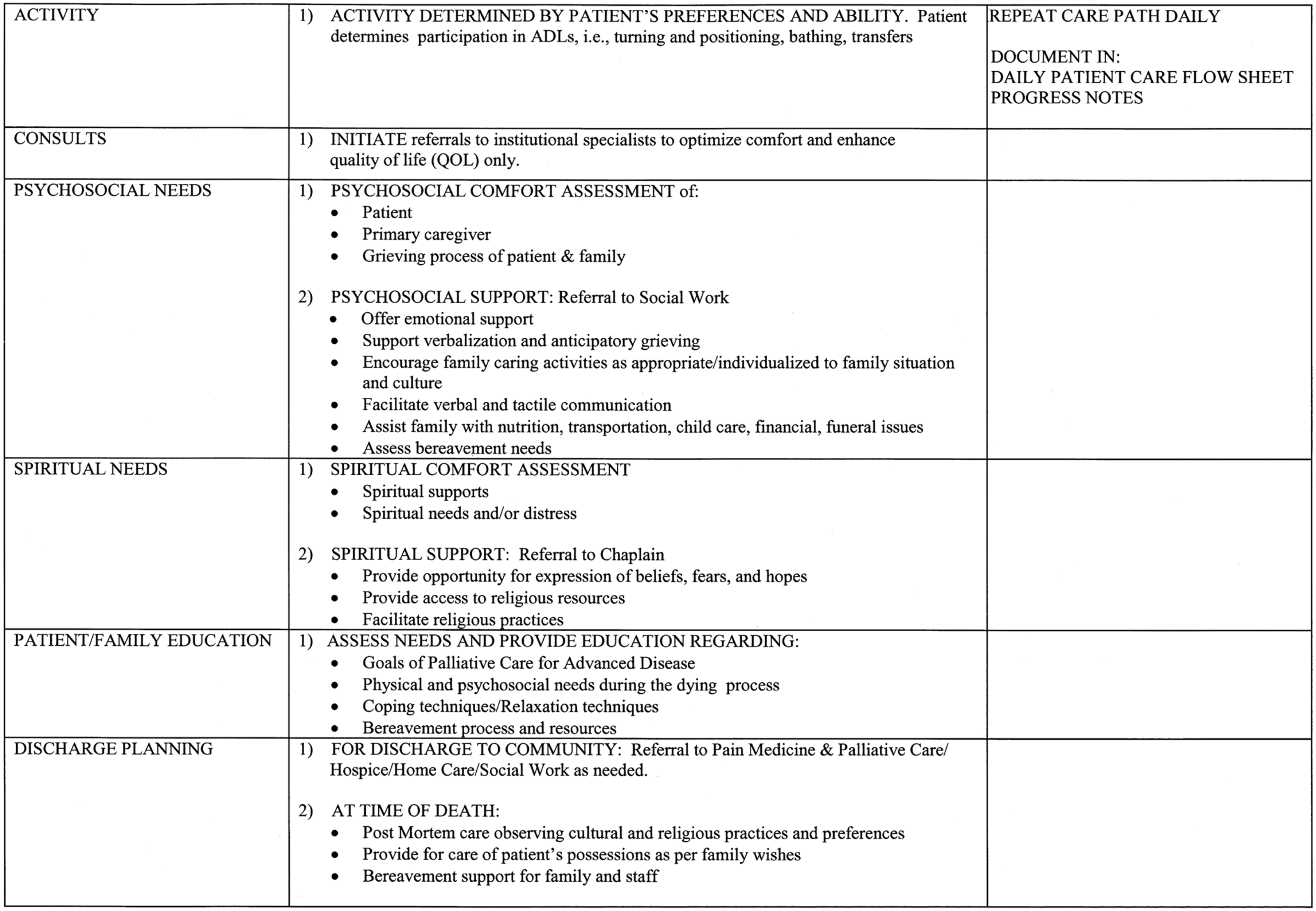
Figure 48A.2 Care path: The interdisciplinary plan of care.

Source: Continuum Health Partners, Inc., Beth Israel Medical Center, Department of Pain Medicine and Palliative Care, New York. Palliative Care for Advanced Disease (PCAD) Care Path; CQI Team on End-of-Life Care.



ACTIVITY	1) ACTIVITY DETERMINED BY PATIENT'S PREFERENCES AND ABILITY. Patient determines participation in ADLs, i.e., turning and positioning, bathing, transfers	REPEAT CARE PATH DAILY DOCUMENT IN: DAILY PATIENT CARE FLOW SHEET PROGRESS NOTES
CONSULTS	1) INITIATE referrals to institutional specialists to optimize comfort and enhance quality of life (QOL) only.	
PSYCHOSOCIAL NEEDS	1) PSYCHOSOCIAL COMFORT ASSESSMENT of: • Patient • Primary caregiver • Grieving process of patient & family 2) PSYCHOSOCIAL SUPPORT: Referral to Social Work • Offer emotional support • Support verbalization and anticipatory grieving • Encourage family caring activities as appropriate/individualized to family situation and culture • Facilitate verbal and tactile communication • Assist family with nutrition, transportation, child care, financial, funeral issues • Assess bereavement needs	
SPIRITUAL NEEDS	1) SPIRITUAL COMFORT ASSESSMENT • Spiritual supports • Spiritual needs and/or distress 2) SPIRITUAL SUPPORT: Referral to Chaplain • Provide opportunity for expression of beliefs, fears, and hopes • Provide access to religious resources • Facilitate religious practices	
PATIENT/FAMILY EDUCATION	1) ASSESS NEEDS AND PROVIDE EDUCATION REGARDING: • Goals of Palliative Care for Advanced Disease • Physical and psychosocial needs during the dying process • Coping techniques/Relaxation techniques • Bereavement process and resources	
DISCHARGE PLANNING	1) FOR DISCHARGE TO COMMUNITY: Referral to Pain Medicine & Palliative Care/ Hospice/Home Care/Social Work as needed. 2) AT TIME OF DEATH: • Post Mortem care observing cultural and religious practices and preferences • Provide for care of patient's possessions as per family wishes • Bereavement support for family and staff	

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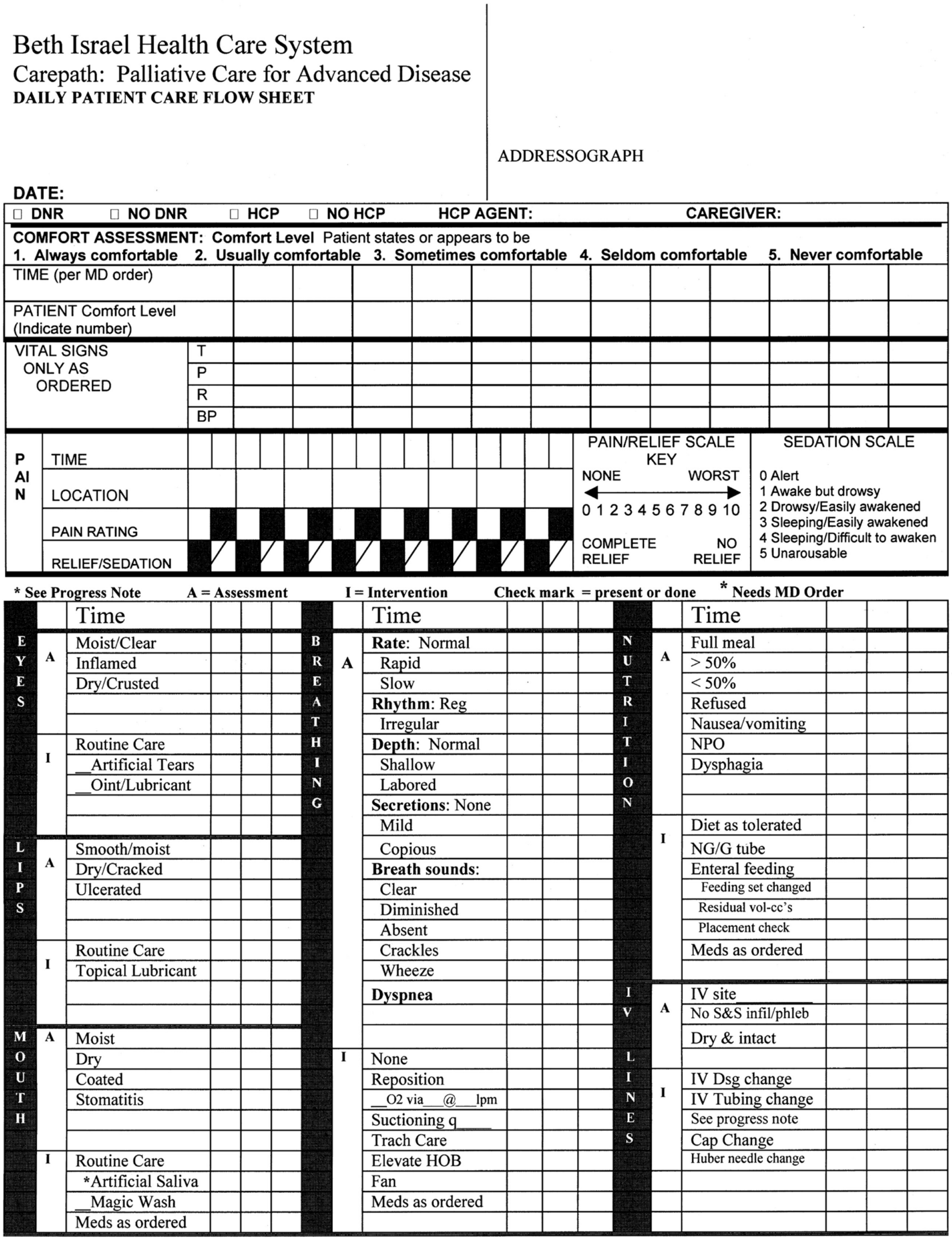
Figure 48A.2 Continued



Beth Israel Health Care System

Carepath: Palliative Care for Advanced Disease

DAILY PATIENT CARE FLOW SHEET

ADDRESSOGRAPH

DATE:

☐ **DNR** ☐ **NO DNR** ☐ **HCP** ☐ **NO HCP** **HCP AGENT:** **CAREGIVER:**

COMFORT ASSESSMENT: Comfort Level Patient states or appears to be

1. Always comfortable 2. Usually comfortable 3. Sometimes comfortable 4. Seldom comfortable 5. Never comfortable

TIME (per MD order)													
PATIENT Comfort Level (Indicate number)													
VITAL SIGNS ONLY AS ORDERED	T												
	P												
	R												
	BP												

PAIN	TIME								
	LOCATION								
	PAIN RATING								
	RELIEF/SEDATION	/	/	/	/	/	/	/	/

PAIN/RELIEF SCALE KEY

NONE ◄——► WORST

0 1 2 3 4 5 6 7 8 9 10

COMPLETE RELIEF — NO RELIEF

SEDATION SCALE

0 Alert
1 Awake but drowsy
2 Drowsy/Easily awakened
3 Sleeping/Easily awakened
4 Sleeping/Difficult to awaken
5 Unarousable

*** See Progress Note A = Assessment I = Intervention Check mark = present or done * Needs MD Order**

		Time			
EYES	**A**	Moist/Clear			
		Inflamed			
		Dry/Crusted			
	I	Routine Care			
		__Artificial Tears			
		__Oint/Lubricant			
LIPS	**A**	Smooth/moist			
		Dry/Cracked			
		Ulcerated			
	I	Routine Care			
		Topical Lubricant			
MOUTH	**A**	Moist			
		Dry			
		Coated			
		Stomatitis			
	I	Routine Care			
		*Artificial Saliva			
		__Magic Wash			
		Meds as ordered			

		Time			
BREATHING	**A**	**Rate**: Normal			
		Rapid			
		Slow			
		Rhythm: Reg			
		Irregular			
		Depth: Normal			
		Shallow			
		Labored			
		Secretions: None			
		Mild			
		Copious			
		Breath sounds:			
		Clear			
		Diminished			
		Absent			
		Crackles			
		Wheeze			
		Dyspnea			
	I	None			
		Reposition			
		__O2 via__@__lpm			
		Suctioning q____			
		Trach Care			
		Elevate HOB			
		Fan			
		Meds as ordered			

		Time			
NUTRITION	**A**	Full meal			
		> 50%			
		< 50%			
		Refused			
		Nausea/vomiting			
		NPO			
		Dysphagia			
	I	Diet as tolerated			
		NG/G tube			
		Enteral feeding			
		Feeding set changed			
		Residual vol-cc's			
		Placement check			
		Meds as ordered			
IV LINES	**A**	IV site____			
		No S&S infil/phleb			
		Dry & intact			
	I	IV Dsg change			
		IV Tubing change			
		See progress note			
		Cap Change			
		Huber needle change			

Figure 48A.3 A daily patient care flow sheet for documentation of assessments and interventions (including automatic referrals to social work and chaplaincy).

Source: Continuum Health Partners, Inc., Beth Israel Medical Center, Department of Pain Medicine and Palliative Care, New York. Palliative Care for Advanced Disease (PCAD) Care Path; CQI Team on End-of-Life Care.

		Time			
MOBILITY	A	Bedbound			
		OOB Chair			
		Amb w Assist			
		OOB ad lib			
		BR Privileges			
	I	T&P per pt comfort			
		ROM q___			
		Assistive Device			
		__Ted Stocking(s)			
		Side Rails Up			
ELIMINATION	A	Voiding qs			
		Anuria			
		Incontinent Urine			
		Bowel Movement			
		Incontinent Feces			
		Diarrhea			
		Constipation			
	I	__Foley Catheter			
		Texas Catheter			
		Inc't Pads			
		__Enema			
		Meds as ordered			
SKIN	A	Normal/Intact			
		Feverish			
		Diaphoretic			
		Pressure Ulcer Stg___			
		Ostomy site D/I			
		Edema___			
		Pruritis			
		Cool/Mottled			
WOUND CARE	I	Site			
		Dressing_______			
		Dry & Intact			
		Drain_________			
		Drainage			
		Odor			
		Ostomy site care			
		Tube site care			

		Time			
SLEEP	A	Normal			
		Interrupted Cycle			
		Insomnia			
	I	Modify Environment			
		Relaxation			
		Meds as order			
PSYCHOSOCIAL	A	Awake/alert			
		Responds to voice			
		Resp to tactile stim			
		Unresponsive			
		Oriented			
		Confused			
		Hallucinating			
		Calm			
		Anxiety			
		Agitated			
		Depression			
		Spiritual distress			
	I	Emotional support			
		Verbal/tactile stimulation			
		Social Worker visit			
		Chaplain visit			

		Time			
FAMILY	A	Engaged w pt			
		Coping w loss			
		Distressed			
	I	Goals of care reviewed			
		Encourage verbal & non-verbal communication w pt			
		Family Meeting			
		Bereavement support			
MISCELLANEOUS		AM Care			
		PM Care			
		PresUlcer Prev Plan			
		Fall Prev Plan			
		Precautions:			
		Isolation:			
		Siderails Up			
		ID Bracelet			
		Allergy Bracelet			
		DNR Bracelet			
		Post Mortem care			

Comments/Progress Notes

PATIENT/FAMILY EDUCATION: **See IPFER**

PCAD Care Path: **Initiated** **Reviewed/Continue With Plan Of Care** **☐ Revised (See Progress Note)**

OTHER NURSING DOCUMENTATION:

☐ **I & O SHEET** ☐ **RESTRAINT FLOW SHEET** ☐ **NEURO-ASSESSMENT** ☐ **OTHER**_______________

SIGNATURE/TITLE	DATE	SHIFT	INITIALS	SIGNATURE/TITLE	DATE	SHIFT	INITIALS
1.				6.			
2.				7.			
3.				8.			
4.				9.			
5.				10.			

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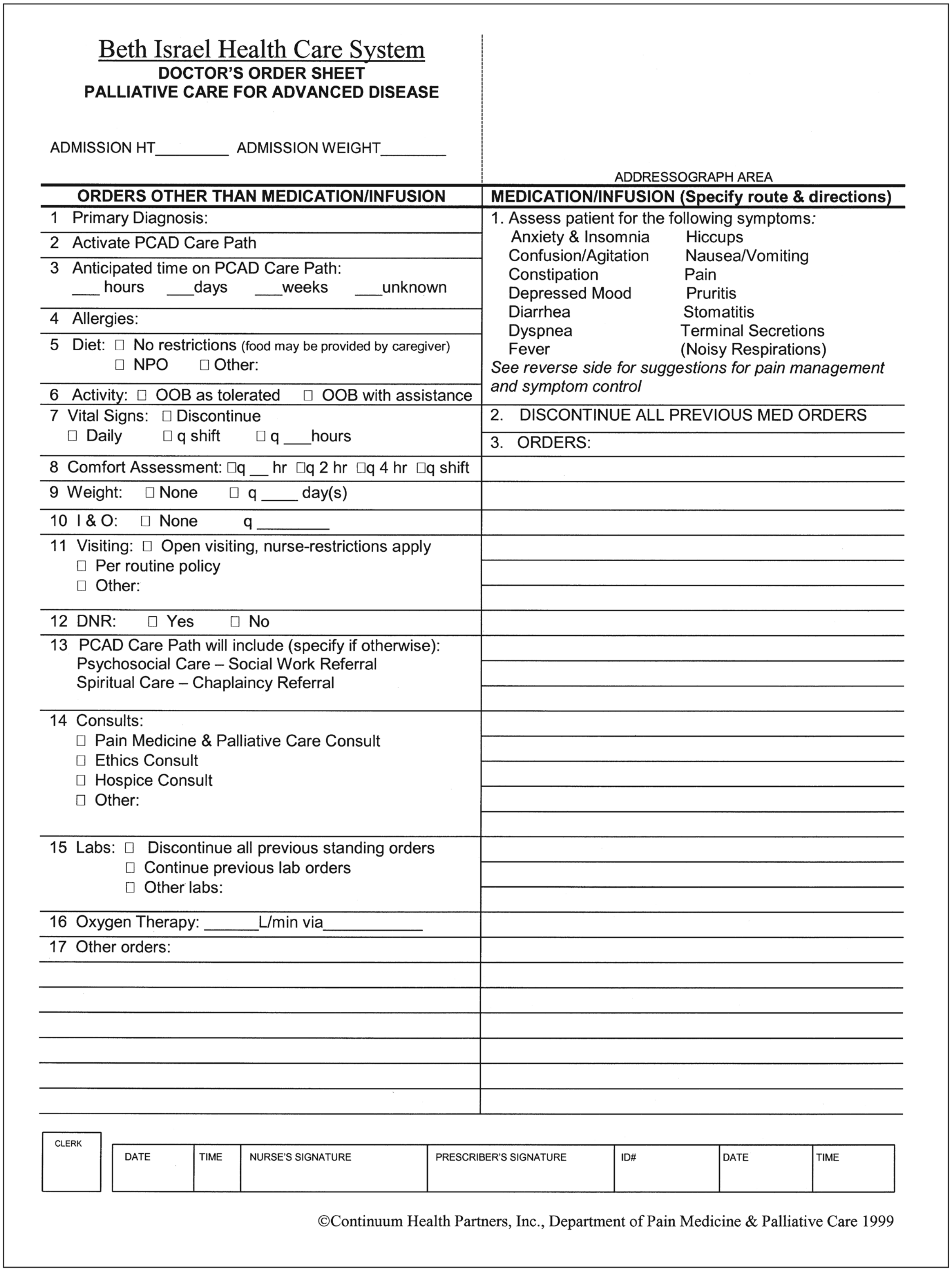
Figure 48A.3 Continued



Beth Israel Health Care System

DOCTOR'S ORDER SHEET

PALLIATIVE CARE FOR ADVANCED DISEASE

ADMISSION HT________ ADMISSION WEIGHT________

ADDRESSOGRAPH AREA

ORDERS OTHER THAN MEDICATION/INFUSION

1 Primary Diagnosis:

2 Activate PCAD Care Path

3 Anticipated time on PCAD Care Path:
___ hours ___days ___weeks ___unknown

4 Allergies:

5 Diet: ☐ No restrictions (food may be provided by caregiver)
☐ NPO ☐ Other:

6 Activity: ☐ OOB as tolerated ☐ OOB with assistance

7 Vital Signs: ☐ Discontinue
☐ Daily ☐ q shift ☐ q ___hours

8 Comfort Assessment: ☐q __ hr ☐q 2 hr ☐q 4 hr ☐q shift

9 Weight: ☐ None ☐ q ____ day(s)

10 I & O: ☐ None q ________

11 Visiting: ☐ Open visiting, nurse-restrictions apply
☐ Per routine policy
☐ Other:

12 DNR: ☐ Yes ☐ No

13 PCAD Care Path will include (specify if otherwise):
Psychosocial Care – Social Work Referral
Spiritual Care – Chaplaincy Referral

14 Consults:
☐ Pain Medicine & Palliative Care Consult
☐ Ethics Consult
☐ Hospice Consult
☐ Other:

15 Labs: ☐ Discontinue all previous standing orders
☐ Continue previous lab orders
☐ Other labs:

16 Oxygen Therapy: ______L/min via___________

17 Other orders:

MEDICATION/INFUSION (Specify route & directions)

1. Assess patient for the following symptoms:

Anxiety & Insomnia	Hiccups
Confusion/Agitation	Nausea/Vomiting
Constipation	Pain
Depressed Mood	Pruritis
Diarrhea	Stomatitis
Dyspnea	Terminal Secretions
Fever	(Noisy Respirations)

See reverse side for suggestions for pain management and symptom control

2. DISCONTINUE ALL PREVIOUS MED ORDERS

3. ORDERS:

CLERK

DATE	TIME	NURSE'S SIGNATURE	PRESCRIBER'S SIGNATURE	ID#	DATE	TIME

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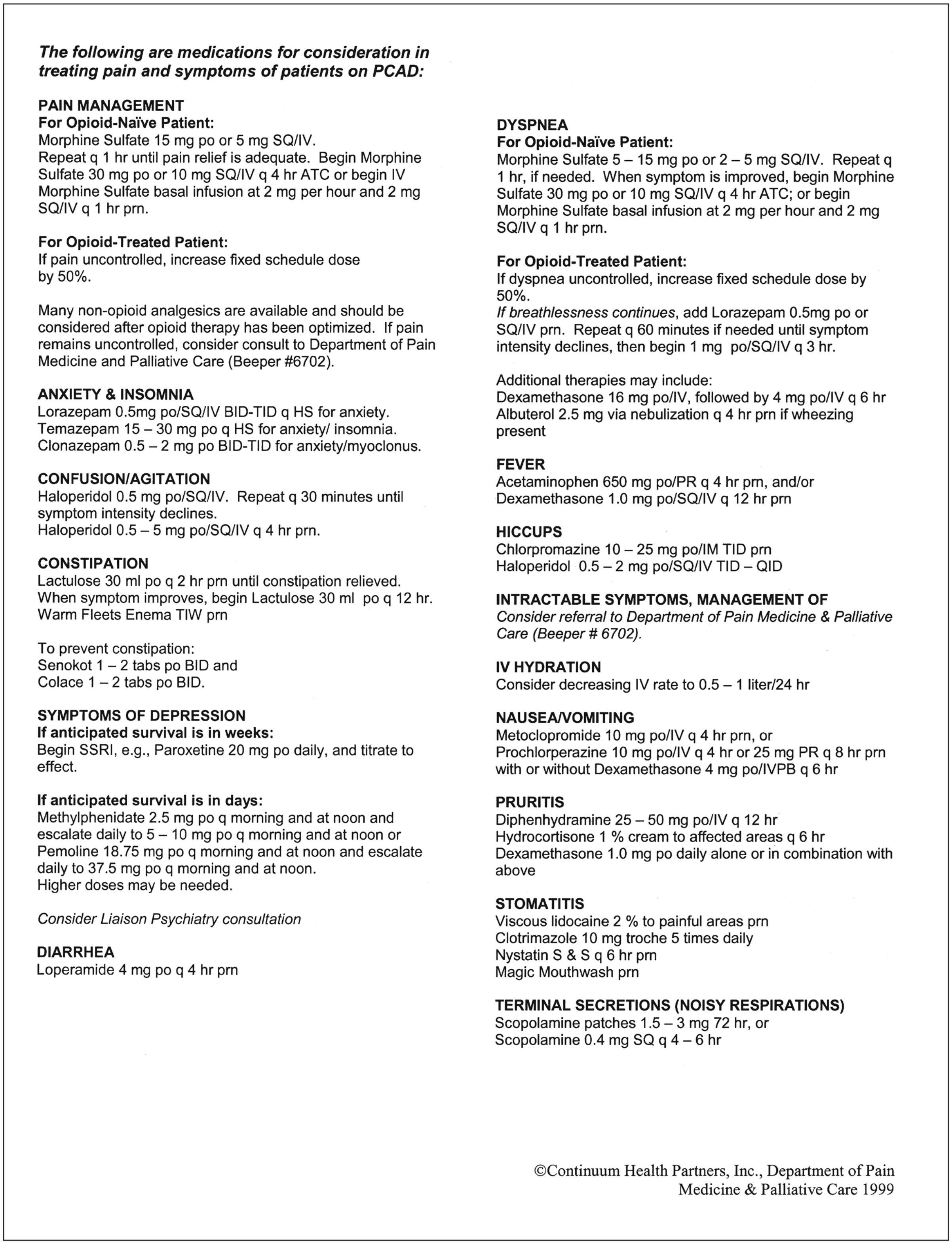
Figure 48A.4 A standardized physician order sheet, with suggestions for medical management of 15 symptoms prevalent at the end of life.

Source: Continuum Health Partners, Inc., Beth Israel Medical Center, Department of Pain Medicine and Palliative Care, New York. Palliative Care for Advanced Disease (PCAD) Care Path; CQI Team on End-of-Life Care.



The following are medications for consideration in treating pain and symptoms of patients on PCAD:

PAIN MANAGEMENT
For Opioid-Naïve Patient:
Morphine Sulfate 15 mg po or 5 mg SQ/IV.
Repeat q 1 hr until pain relief is adequate. Begin Morphine Sulfate 30 mg po or 10 mg SQ/IV q 4 hr ATC or begin IV Morphine Sulfate basal infusion at 2 mg per hour and 2 mg SQ/IV q 1 hr prn.

For Opioid-Treated Patient:
If pain uncontrolled, increase fixed schedule dose by 50%.

Many non-opioid analgesics are available and should be considered after opioid therapy has been optimized. If pain remains uncontrolled, consider consult to Department of Pain Medicine and Palliative Care (Beeper #6702).

ANXIETY & INSOMNIA
Lorazepam 0.5mg po/SQ/IV BID-TID q HS for anxiety.
Temazepam 15 – 30 mg po q HS for anxiety/ insomnia.
Clonazepam 0.5 – 2 mg po BID-TID for anxiety/myoclonus.

CONFUSION/AGITATION
Haloperidol 0.5 mg po/SQ/IV. Repeat q 30 minutes until symptom intensity declines.
Haloperidol 0.5 – 5 mg po/SQ/IV q 4 hr prn.

CONSTIPATION
Lactulose 30 ml po q 2 hr prn until constipation relieved.
When symptom improves, begin Lactulose 30 ml po q 12 hr.
Warm Fleets Enema TIW prn

To prevent constipation:
Senokot 1 – 2 tabs po BID and
Colace 1 – 2 tabs po BID.

SYMPTOMS OF DEPRESSION
If anticipated survival is in weeks:
Begin SSRI, e.g., Paroxetine 20 mg po daily, and titrate to effect.

If anticipated survival is in days:
Methylphenidate 2.5 mg po q morning and at noon and escalate daily to 5 – 10 mg po q morning and at noon or Pemoline 18.75 mg po q morning and at noon and escalate daily to 37.5 mg po q morning and at noon.
Higher doses may be needed.

Consider Liaison Psychiatry consultation

DIARRHEA
Loperamide 4 mg po q 4 hr prn

DYSPNEA
For Opioid-Naïve Patient:
Morphine Sulfate 5 – 15 mg po or 2 – 5 mg SQ/IV. Repeat q 1 hr, if needed. When symptom is improved, begin Morphine Sulfate 30 mg po or 10 mg SQ/IV q 4 hr ATC; or begin Morphine Sulfate basal infusion at 2 mg per hour and 2 mg SQ/IV q 1 hr prn.

For Opioid-Treated Patient:
If dyspnea uncontrolled, increase fixed schedule dose by 50%.
If breathlessness continues, add Lorazepam 0.5mg po or SQ/IV prn. Repeat q 60 minutes if needed until symptom intensity declines, then begin 1 mg po/SQ/IV q 3 hr.

Additional therapies may include:
Dexamethasone 16 mg po/IV, followed by 4 mg po/IV q 6 hr
Albuterol 2.5 mg via nebulization q 4 hr prn if wheezing present

FEVER
Acetaminophen 650 mg po/PR q 4 hr prn, and/or
Dexamethasone 1.0 mg po/SQ/IV q 12 hr prn

HICCUPS
Chlorpromazine 10 – 25 mg po/IM TID prn
Haloperidol 0.5 – 2 mg po/SQ/IV TID – QID

INTRACTABLE SYMPTOMS, MANAGEMENT OF
Consider referral to Department of Pain Medicine & Palliative Care (Beeper # 6702).

IV HYDRATION
Consider decreasing IV rate to 0.5 – 1 liter/24 hr

NAUSEA/VOMITING
Metoclopromide 10 mg po/IV q 4 hr prn, or
Prochlorperazine 10 mg po/IV q 4 hr or 25 mg PR q 8 hr prn with or without Dexamethasone 4 mg po/IVPB q 6 hr

PRURITIS
Diphenhydramine 25 – 50 mg po/IV q 12 hr
Hydrocortisone 1 % cream to affected areas q 6 hr
Dexamethasone 1.0 mg po daily alone or in combination with above

STOMATITIS
Viscous lidocaine 2 % to painful areas prn
Clotrimazole 10 mg troche 5 times daily
Nystatin S & S q 6 hr prn
Magic Mouthwash prn

TERMINAL SECRETIONS (NOISY RESPIRATIONS)
Scopolamine patches 1.5 – 3 mg 72 hr, or
Scopolamine 0.4 mg SQ q 4 – 6 hr

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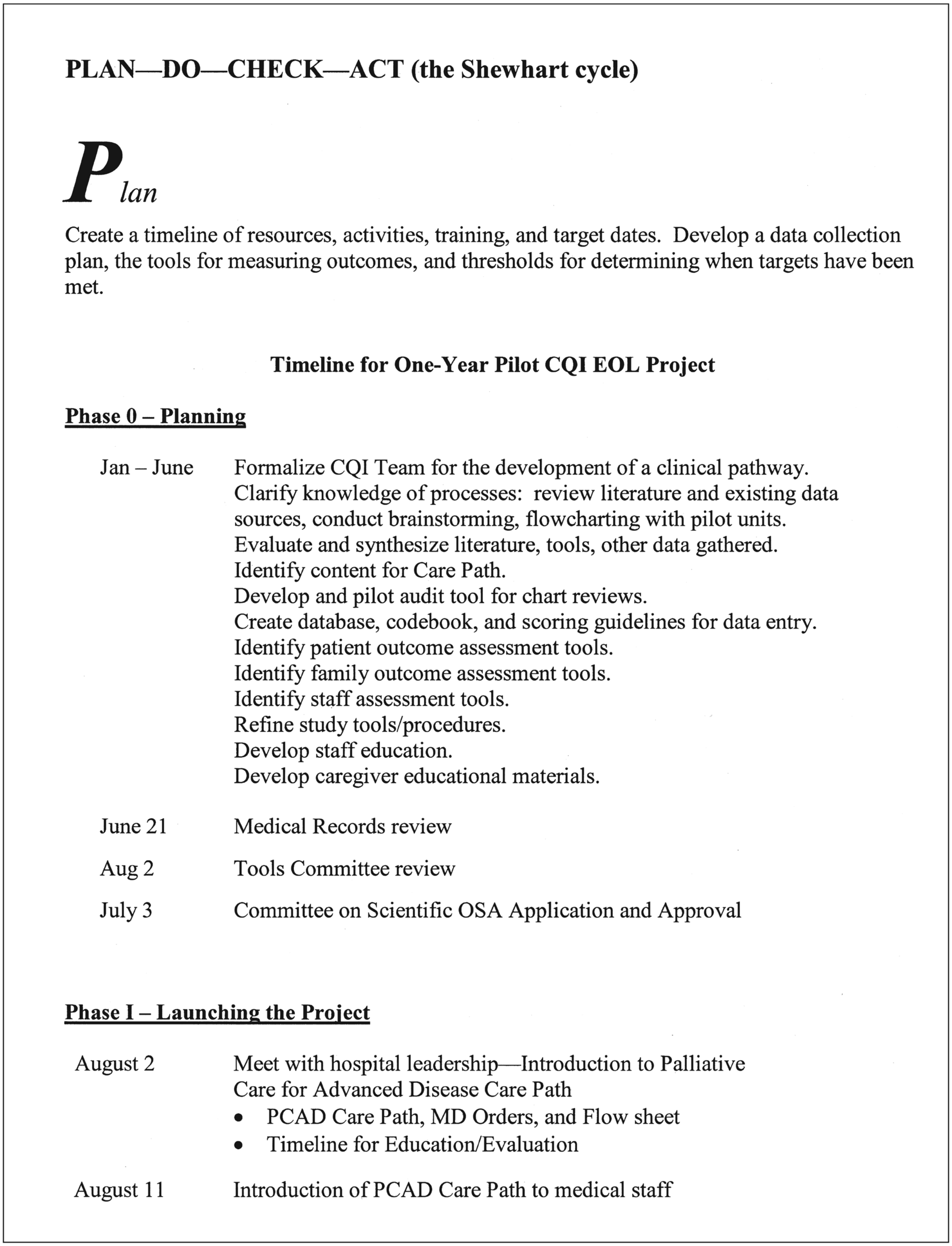
Figure 48A.4 Continued



PLAN—DO—CHECK—ACT (the Shewhart cycle)

Plan

Create a timeline of resources, activities, training, and target dates. Develop a data collection plan, the tools for measuring outcomes, and thresholds for determining when targets have been met.

Timeline for One-Year Pilot CQI EOL Project

Phase 0 – Planning

Jan – June	Formalize CQI Team for the development of a clinical pathway. Clarify knowledge of processes: review literature and existing data sources, conduct brainstorming, flowcharting with pilot units. Evaluate and synthesize literature, tools, other data gathered. Identify content for Care Path. Develop and pilot audit tool for chart reviews. Create database, codebook, and scoring guidelines for data entry. Identify patient outcome assessment tools. Identify family outcome assessment tools. Identify staff assessment tools. Refine study tools/procedures. Develop staff education. Develop caregiver educational materials.
June 21	Medical Records review
Aug 2	Tools Committee review
July 3	Committee on Scientific OSA Application and Approval

Phase I – Launching the Project

August 2	Meet with hospital leadership—Introduction to Palliative Care for Advanced Disease Care Path • PCAD Care Path, MD Orders, and Flow sheet • Timeline for Education/Evaluation
August 11	Introduction of PCAD Care Path to medical staff

Figure 48A.5 The PDCA portion of the FOCUS-PDCA cycle.

Source: Continuum Health Partners, Inc., Beth Israel Medical Center, Department of Pain Medicine and Palliative Care, New York. Palliative Care for Advanced Disease (PCAD) Care Path; CQI Team on End-of-Life Care.

Phase II – Unit Implementation and Education of PCAD Care Path

	Cohort 1	Cohort 2		Cohort 3
Meet with unit leaders of pilot units	June 21	September 15	July 21	October 11
Pre-test	August 23–25	September 27	September 14	TBS
Unit leadership team meeting	TBS	October 5	October 12	TBS
Introduction of PCAD Care Path to unit staff	August 31–September 1	September 27–September 30	October 22	TBS
In-service of unit staff	September 1 September 2 September 3	October 4–October 6	October 25–October 26	TBS TBS TBS
Rollout of Care Path	September 6	October 11	November 1	TBS
Brainstorming—educational needs	October 11	November 8	December 13	December 6
Educational series	September–February	October– March	November–April	November–April
Focus groups	October & January	November & February	December & March	December & March
Feedback / closure / continuation	March	April	May	May
Post-test	March	April	May	May

Phase III – Evaluation

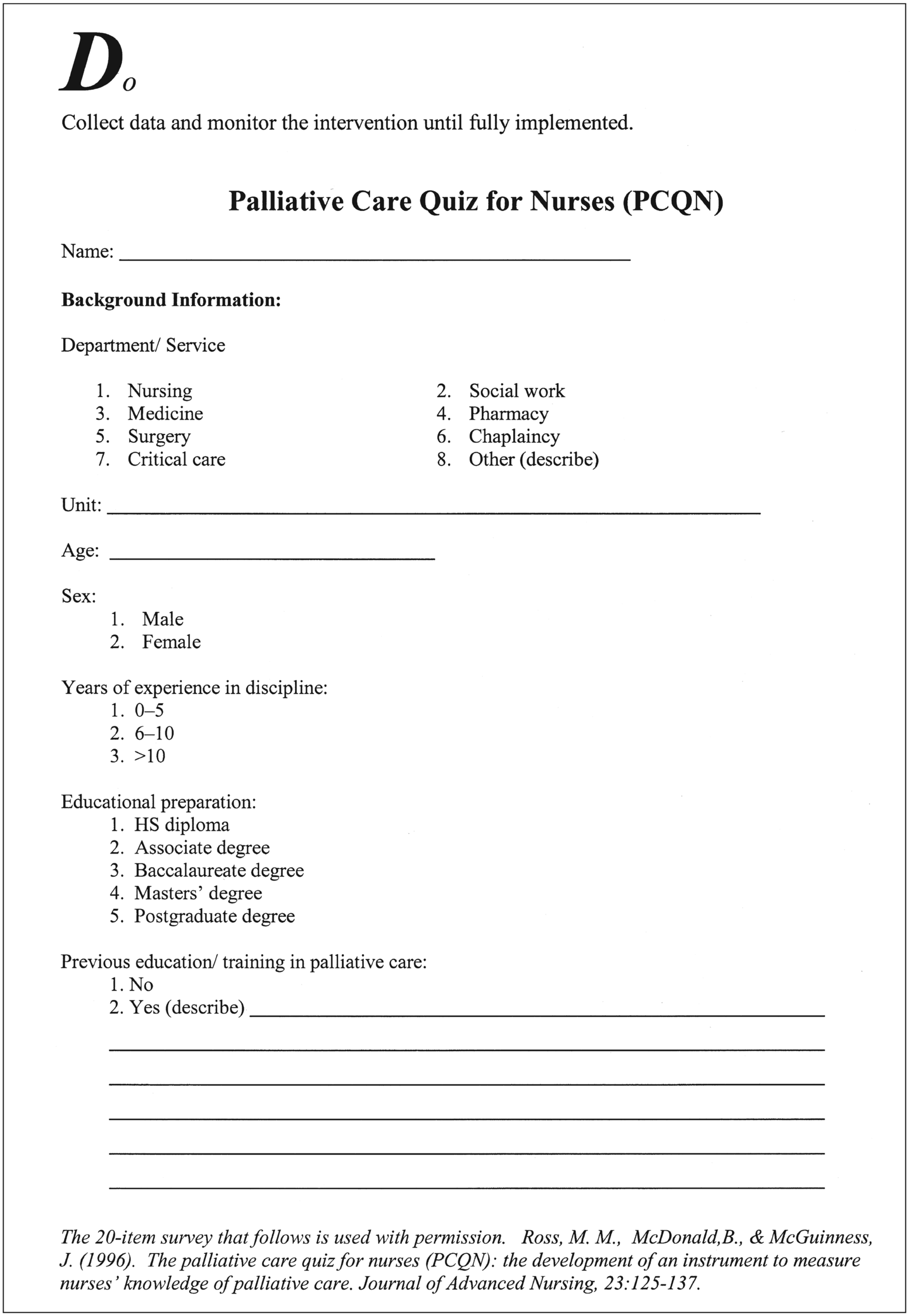
Chart Reviews using Chart Audit Tool (CAT) (Total =330)

June–Aug	• 20 retrospective audits for 5 pilot units	(Total = 100)
Sep 1999–Mar 2002	• 20 retrospective audits for 2 control units	(Total = 40)
	• 10 during implementation audits for 5 pilot units	(Total = 50)
	• 20 post implementation audits for 5 pilot units	(Total = 100)
	• 20 post implementation audits for 2 control units	(Total = 40)
	Each patient on PCAD Care Path as admitted.	
Sep 1999–Mar 2002	Tool: Teno's After Death (interview or mailed survey)	
Dates TBD	Staff survey post-tests (4 mo post-initiation of PCAD) Tool: Palliative Care Quiz	
Sep 1999–Mar 2002	Process Audits (PAT) Ongoing throughout time patient on PCAD Care Path	
Sep 1999–Mar 2002	Brainstorming sessions and focus groups with staff to identify education 1–2 mo after each unit begins PCAD	

Phase IV – Reporting

April 15, 2002	Report to grant agency, hospital, and unit staff

Figure 48A.5 Continued



*D*o

Collect data and monitor the intervention until fully implemented.

Palliative Care Quiz for Nurses (PCQN)

Name: ____

Background Information:

Department/ Service

1. Nursing
2. Social work
3. Medicine
4. Pharmacy
5. Surgery
6. Chaplaincy
7. Critical care
8. Other (describe)

Unit: ____

Age: ____________________________

Sex:
1. Male
2. Female

Years of experience in discipline:
1. 0–5
2. 6–10
3. >10

Educational preparation:
1. HS diploma
2. Associate degree
3. Baccalaureate degree
4. Masters' degree
5. Postgraduate degree

Previous education/ training in palliative care:
1. No
2. Yes (describe) ____

____

____

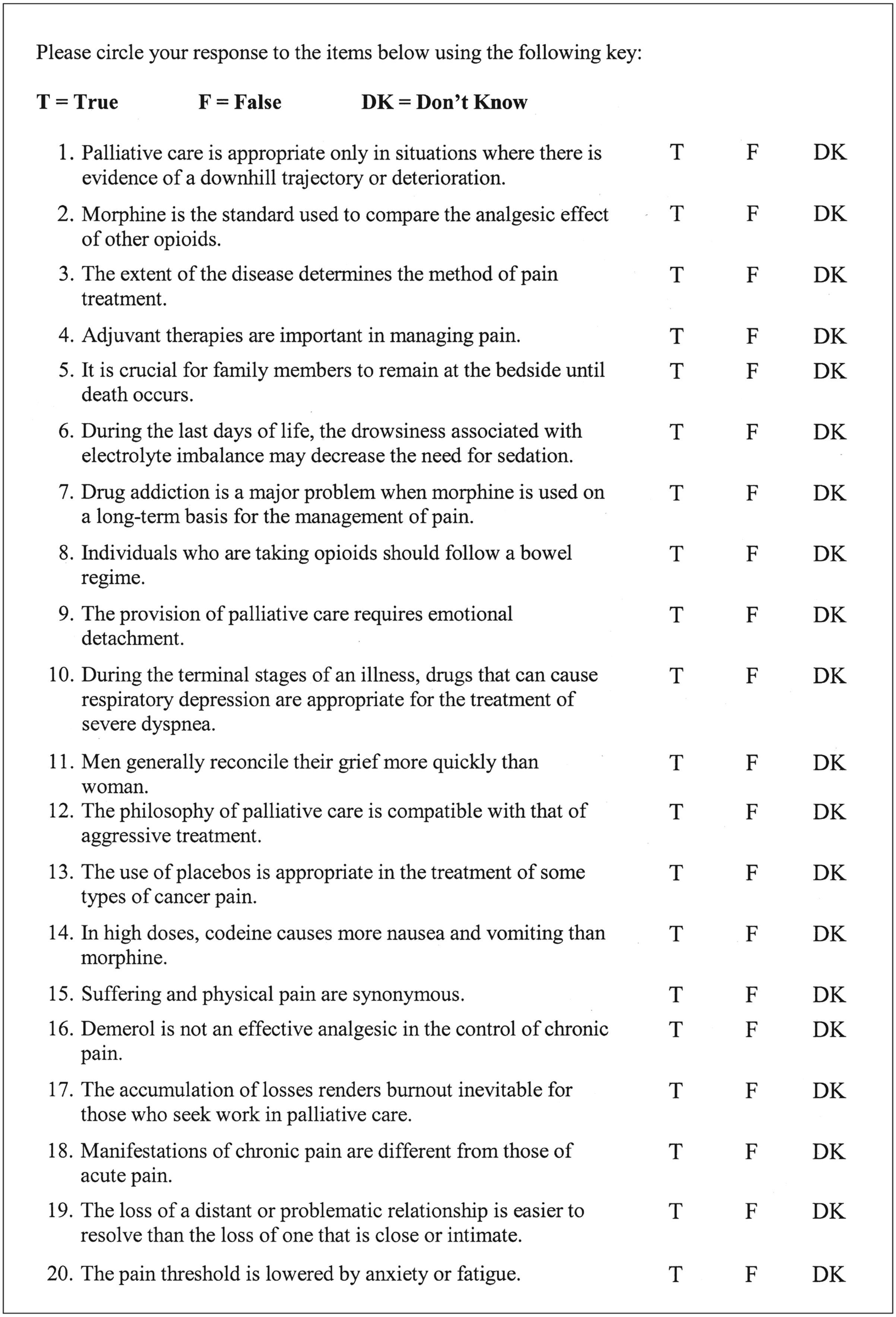
____

____

____

The 20-item survey that follows is used with permission. Ross, M. M., McDonald,B., & McGuinness, J. (1996). The palliative care quiz for nurses (PCQN): the development of an instrument to measure nurses' knowledge of palliative care. Journal of Advanced Nursing, 23:125-137.

Figure 48A.5 Continued



Please circle your response to the items below using the following key:

T = True **F = False** **DK = Don't Know**

1. Palliative care is appropriate only in situations where there is evidence of a downhill trajectory or deterioration.	T	F	DK
2. Morphine is the standard used to compare the analgesic effect of other opioids.	T	F	DK
3. The extent of the disease determines the method of pain treatment.	T	F	DK
4. Adjuvant therapies are important in managing pain.	T	F	DK
5. It is crucial for family members to remain at the bedside until death occurs.	T	F	DK
6. During the last days of life, the drowsiness associated with electrolyte imbalance may decrease the need for sedation.	T	F	DK
7. Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain.	T	F	DK
8. Individuals who are taking opioids should follow a bowel regime.	T	F	DK
9. The provision of palliative care requires emotional detachment.	T	F	DK
10. During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnea.	T	F	DK
11. Men generally reconcile their grief more quickly than woman.	T	F	DK
12. The philosophy of palliative care is compatible with that of aggressive treatment.	T	F	DK
13. The use of placebos is appropriate in the treatment of some types of cancer pain.	T	F	DK
14. In high doses, codeine causes more nausea and vomiting than morphine.	T	F	DK
15. Suffering and physical pain are synonymous.	T	F	DK
16. Demerol is not an effective analgesic in the control of chronic pain.	T	F	DK
17. The accumulation of losses renders burnout inevitable for those who seek work in palliative care.	T	F	DK
18. Manifestations of chronic pain are different from those of acute pain.	T	F	DK
19. The loss of a distant or problematic relationship is easier to resolve than the loss of one that is close or intimate.	T	F	DK
20. The pain threshold is lowered by anxiety or fatigue.	T	F	DK

Figure 48A.5 Continued

Check

Analyze findings, graph results, and evaluate reasons for variations. If targets are reached, set a date to stop or decrease the frequency of monitoring. Summarize what was learned.

Sample: Results of Palliative Care Knowledge Quiz, Preimplementation of PCAD

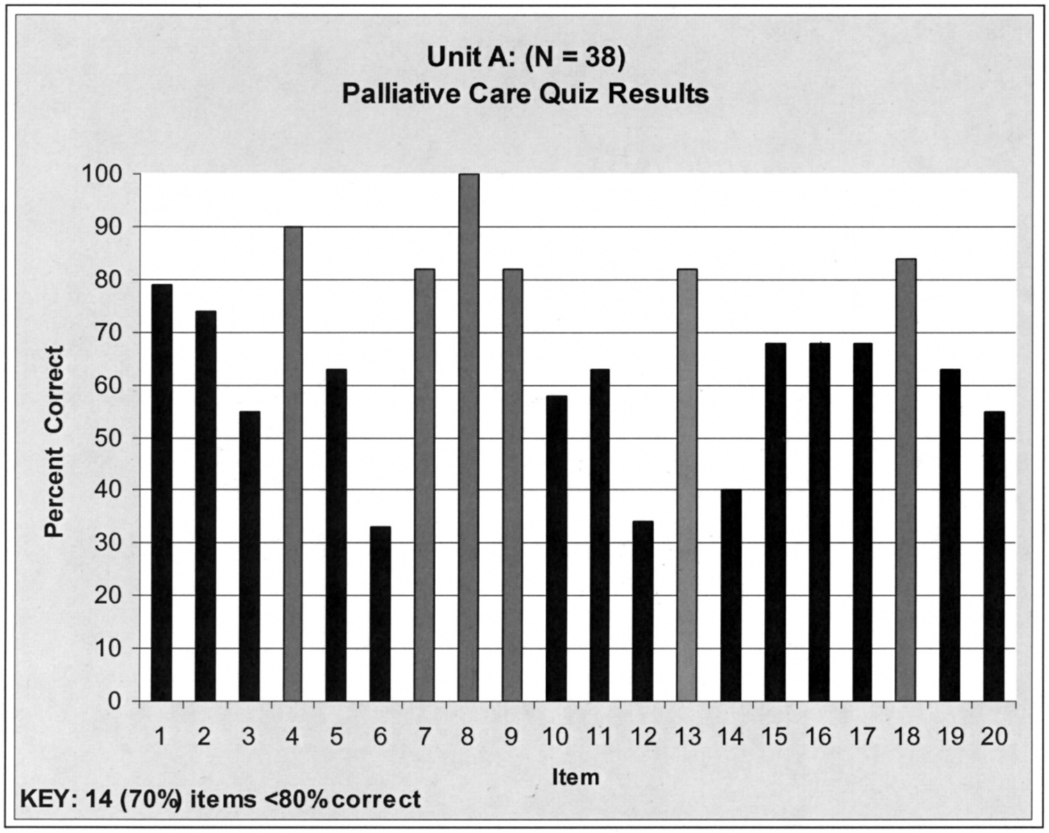
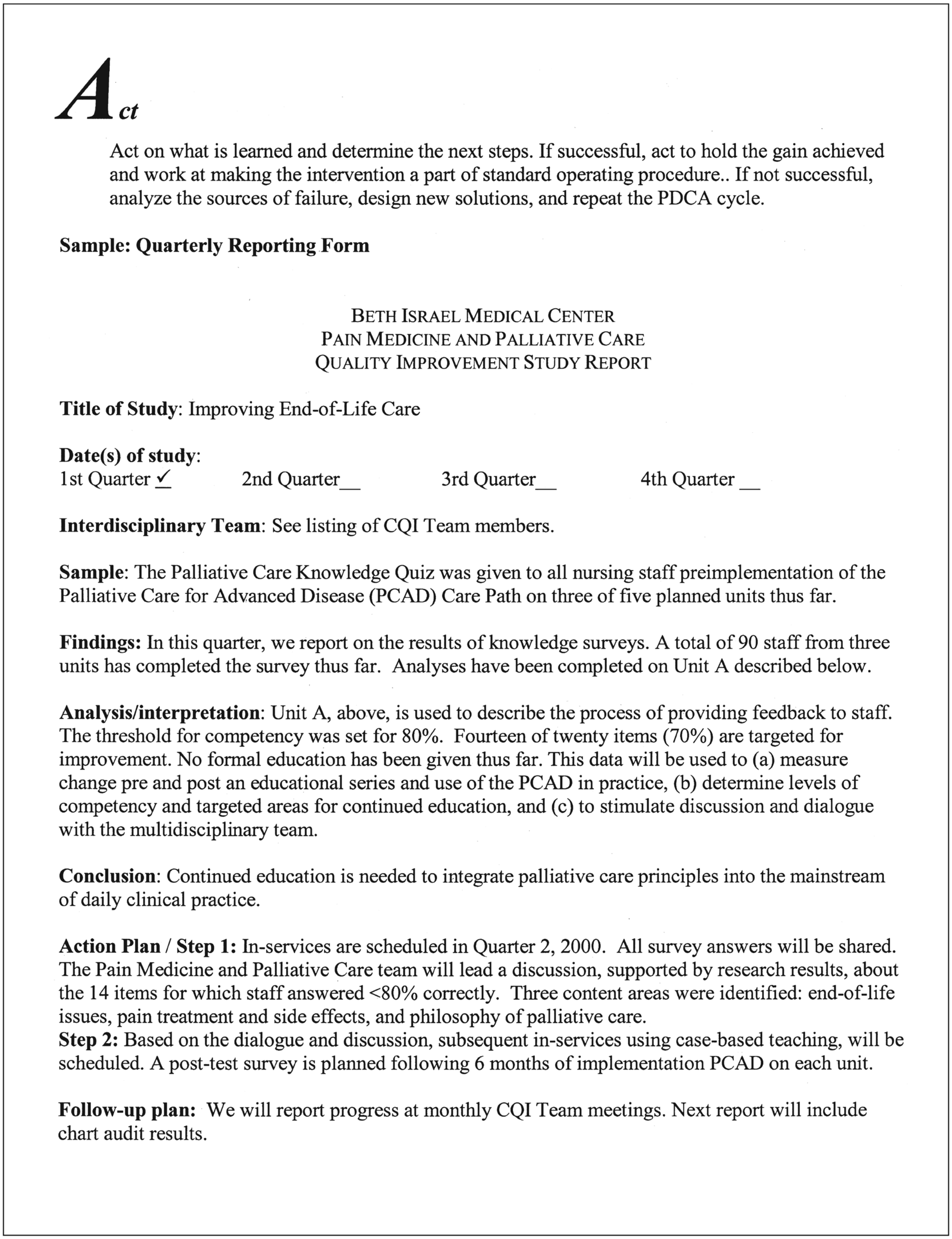


Figure 48A.5 Continued



Act

Act on what is learned and determine the next steps. If successful, act to hold the gain achieved and work at making the intervention a part of standard operating procedure.. If not successful, analyze the sources of failure, design new solutions, and repeat the PDCA cycle.

Sample: Quarterly Reporting Form

BETH ISRAEL MEDICAL CENTER
PAIN MEDICINE AND PALLIATIVE CARE
QUALITY IMPROVEMENT STUDY REPORT

Title of Study: Improving End-of-Life Care

Date(s) of study:
1st Quarter ✓ 2nd Quarter__ 3rd Quarter__ 4th Quarter __

Interdisciplinary Team: See listing of CQI Team members.

Sample: The Palliative Care Knowledge Quiz was given to all nursing staff preimplementation of the Palliative Care for Advanced Disease (PCAD) Care Path on three of five planned units thus far.

Findings: In this quarter, we report on the results of knowledge surveys. A total of 90 staff from three units has completed the survey thus far. Analyses have been completed on Unit A described below.

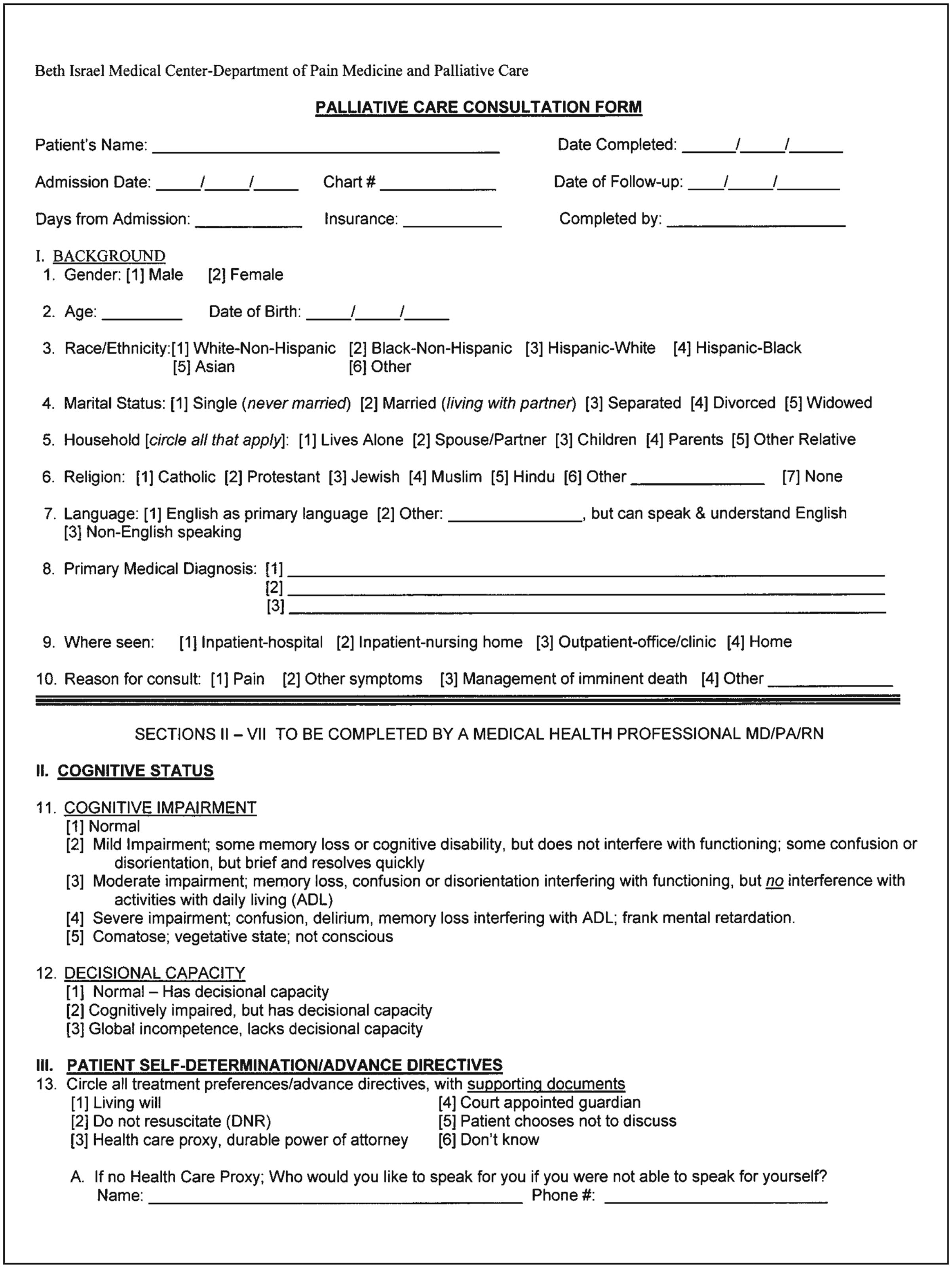
Analysis/interpretation: Unit A, above, is used to describe the process of providing feedback to staff. The threshold for competency was set for 80%. Fourteen of twenty items (70%) are targeted for improvement. No formal education has been given thus far. This data will be used to (a) measure change pre and post an educational series and use of the PCAD in practice, (b) determine levels of competency and targeted areas for continued education, and (c) to stimulate discussion and dialogue with the multidisciplinary team.

Conclusion: Continued education is needed to integrate palliative care principles into the mainstream of daily clinical practice.

Action Plan / Step 1: In-services are scheduled in Quarter 2, 2000. All survey answers will be shared. The Pain Medicine and Palliative Care team will lead a discussion, supported by research results, about the 14 items for which staff answered <80% correctly. Three content areas were identified: end-of-life issues, pain treatment and side effects, and philosophy of palliative care.
Step 2: Based on the dialogue and discussion, subsequent in-services using case-based teaching, will be scheduled. A post-test survey is planned following 6 months of implementation PCAD on each unit.

Follow-up plan: We will report progress at monthly CQI Team meetings. Next report will include chart audit results.

Figure 48A.5 Continued



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PALLIATIVE CARE CONSULTATION FORM

Patient's Name: ______________________________ Date Completed: _____/_____/_____

Admission Date: _____/_____/_____ Chart # ____________ Date of Follow-up: ____/_____/______

Days from Admission: ___________ Insurance: ___________ Completed by: ___________________

I. BACKGROUND

1. Gender: [1] Male [2] Female
2. Age: _________ Date of Birth: _____/_____/_____
3. Race/Ethnicity: [1] White-Non-Hispanic [2] Black-Non-Hispanic [3] Hispanic-White [4] Hispanic-Black [5] Asian [6] Other
4. Marital Status: [1] Single (*never married*) [2] Married (*living with partner*) [3] Separated [4] Divorced [5] Widowed
5. Household [*circle all that apply*]: [1] Lives Alone [2] Spouse/Partner [3] Children [4] Parents [5] Other Relative
6. Religion: [1] Catholic [2] Protestant [3] Jewish [4] Muslim [5] Hindu [6] Other ______________ [7] None
7. Language: [1] English as primary language [2] Other: ______________, but can speak & understand English
   [3] Non-English speaking
8. Primary Medical Diagnosis: [1] ____
   [2] ____
   [3] ____
9. Where seen: [1] Inpatient-hospital [2] Inpatient-nursing home [3] Outpatient-office/clinic [4] Home
10. Reason for consult: [1] Pain [2] Other symptoms [3] Management of imminent death [4] Other ____________

SECTIONS II – VII TO BE COMPLETED BY A MEDICAL HEALTH PROFESSIONAL MD/PA/RN

II. COGNITIVE STATUS

11. COGNITIVE IMPAIRMENT
    [1] Normal
    [2] Mild Impairment; some memory loss or cognitive disability, but does not interfere with functioning; some confusion or disorientation, but brief and resolves quickly
    [3] Moderate impairment; memory loss, confusion or disorientation interfering with functioning, but *no* interference with activities with daily living (ADL)
    [4] Severe impairment; confusion, delirium, memory loss interfering with ADL; frank mental retardation.
    [5] Comatose; vegetative state; not conscious
12. DECISIONAL CAPACITY
    [1] Normal – Has decisional capacity
    [2] Cognitively impaired, but has decisional capacity
    [3] Global incompetence, lacks decisional capacity

III. PATIENT SELF-DETERMINATION/ADVANCE DIRECTIVES

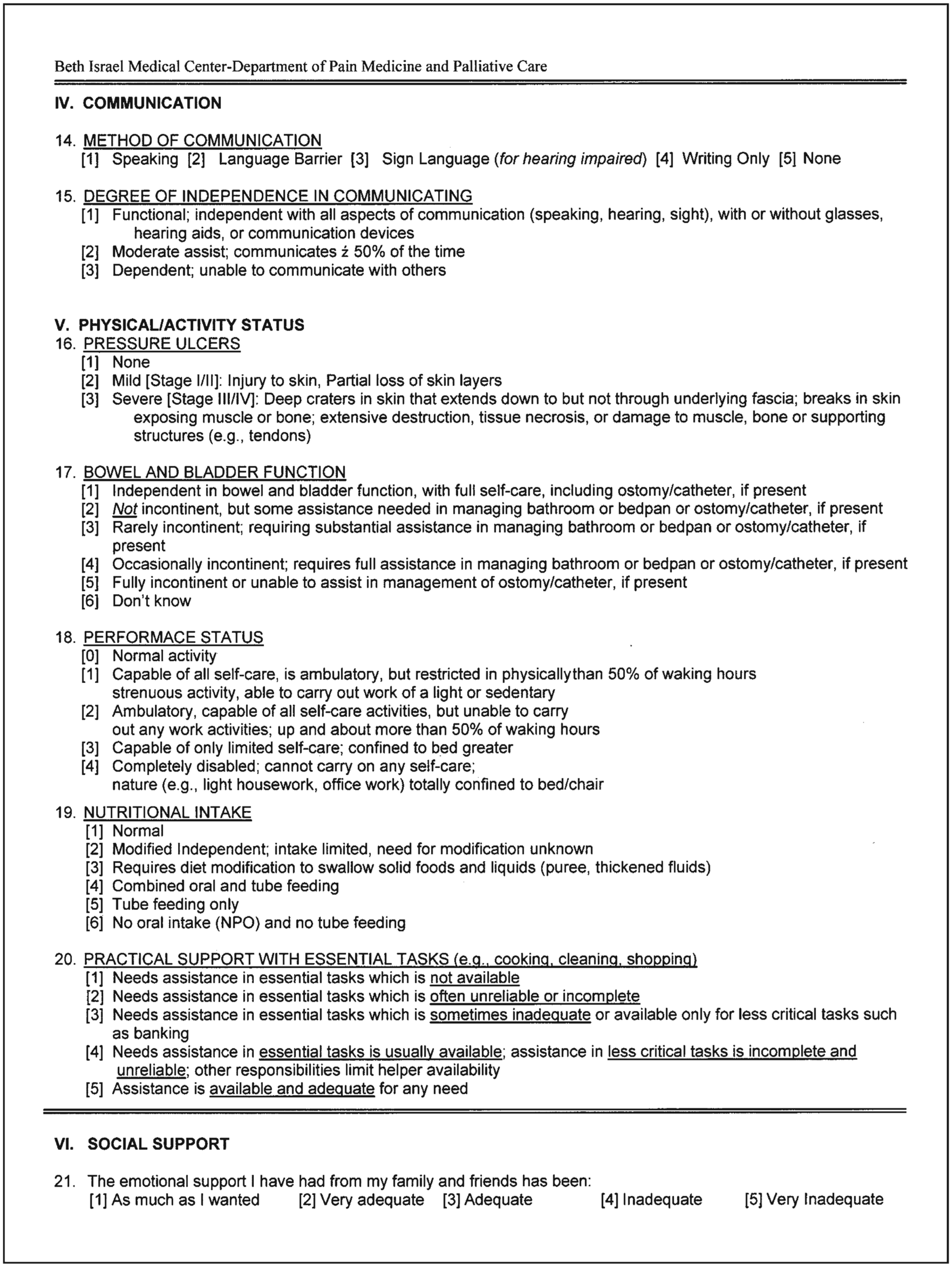
13. Circle all treatment preferences/advance directives, with supporting documents

[1] Living will	[4] Court appointed guardian
[2] Do not resuscitate (DNR)	[5] Patient chooses not to discuss
[3] Health care proxy, durable power of attorney	[6] Don't know

A. If no Health Care Proxy; Who would you like to speak for you if you were not able to speak for yourself?
Name: ________________________________ Phone #: ____________________

Figure 48A.6 Palliative care consultation form.

Source: Continuum Health Partners, Inc., Beth Israel Medical Center, Department of Pain Medicine and Palliative Care, New York. Palliative Care for Advanced Disease (PCAD) Care Path; CQI Team on End-of-Life Care.



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IV. COMMUNICATION

14. METHOD OF COMMUNICATION
    [1] Speaking [2] Language Barrier [3] Sign Language (*for hearing impaired*) [4] Writing Only [5] None

15. DEGREE OF INDEPENDENCE IN COMMUNICATING
    [1] Functional; independent with all aspects of communication (speaking, hearing, sight), with or without glasses, hearing aids, or communication devices
    [2] Moderate assist; communicates ż 50% of the time
    [3] Dependent; unable to communicate with others

V. PHYSICAL/ACTIVITY STATUS

16. PRESSURE ULCERS
    [1] None
    [2] Mild [Stage I/II]: Injury to skin, Partial loss of skin layers
    [3] Severe [Stage III/IV]: Deep craters in skin that extends down to but not through underlying fascia; breaks in skin exposing muscle or bone; extensive destruction, tissue necrosis, or damage to muscle, bone or supporting structures (e.g., tendons)

17. BOWEL AND BLADDER FUNCTION
    [1] Independent in bowel and bladder function, with full self-care, including ostomy/catheter, if present
    [2] *Not* incontinent, but some assistance needed in managing bathroom or bedpan or ostomy/catheter, if present
    [3] Rarely incontinent; requiring substantial assistance in managing bathroom or bedpan or ostomy/catheter, if present
    [4] Occasionally incontinent; requires full assistance in managing bathroom or bedpan or ostomy/catheter, if present
    [5] Fully incontinent or unable to assist in management of ostomy/catheter, if present
    [6] Don't know

18. PERFORMACE STATUS
    [0] Normal activity
    [1] Capable of all self-care, is ambulatory, but restricted in physicallythan 50% of waking hours strenuous activity, able to carry out work of a light or sedentary
    [2] Ambulatory, capable of all self-care activities, but unable to carry out any work activities; up and about more than 50% of waking hours
    [3] Capable of only limited self-care; confined to bed greater
    [4] Completely disabled; cannot carry on any self-care; nature (e.g., light housework, office work) totally confined to bed/chair

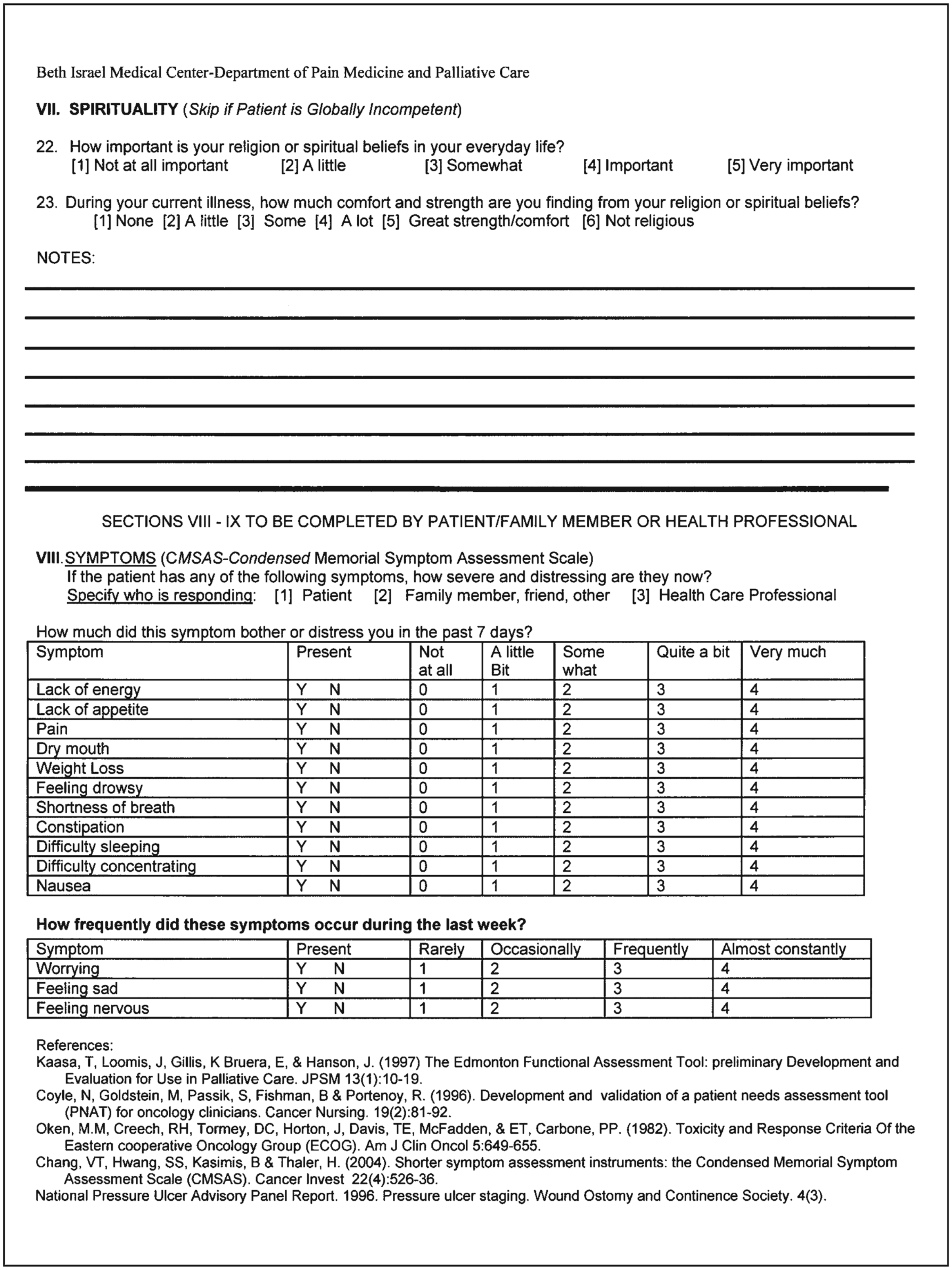
19. NUTRITIONAL INTAKE
    [1] Normal
    [2] Modified Independent; intake limited, need for modification unknown
    [3] Requires diet modification to swallow solid foods and liquids (puree, thickened fluids)
    [4] Combined oral and tube feeding
    [5] Tube feeding only
    [6] No oral intake (NPO) and no tube feeding

20. PRACTICAL SUPPORT WITH ESSENTIAL TASKS (e.g., cooking, cleaning, shopping)
    [1] Needs assistance in essential tasks which is not available
    [2] Needs assistance in essential tasks which is often unreliable or incomplete
    [3] Needs assistance in essential tasks which is sometimes inadequate or available only for less critical tasks such as banking
    [4] Needs assistance in essential tasks is usually available; assistance in less critical tasks is incomplete and unreliable; other responsibilities limit helper availability
    [5] Assistance is available and adequate for any need

VI. SOCIAL SUPPORT

21. The emotional support I have had from my family and friends has been:
    [1] As much as I wanted [2] Very adequate [3] Adequate [4] Inadequate [5] Very Inadequate

Figure 48A.6 Continued



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VII. SPIRITUALITY (*Skip if Patient is Globally Incompetent*)

22. How important is your religion or spiritual beliefs in your everyday life?
[1] Not at all important [2] A little [3] Somewhat [4] Important [5] Very important

23. During your current illness, how much comfort and strength are you finding from your religion or spiritual beliefs?
[1] None [2] A little [3] Some [4] A lot [5] Great strength/comfort [6] Not religious

NOTES:

SECTIONS VIII - IX TO BE COMPLETED BY PATIENT/FAMILY MEMBER OR HEALTH PROFESSIONAL

VIII. SYMPTOMS (C*MSAS-Condensed* Memorial Symptom Assessment Scale)
If the patient has any of the following symptoms, how severe and distressing are they now?
Specify who is responding: [1] Patient [2] Family member, friend, other [3] Health Care Professional

How much did this symptom bother or distress you in the past 7 days?

Symptom	Present	Not at all	A little Bit	Some what	Quite a bit	Very much
Lack of energy	Y N	0	1	2	3	4
Lack of appetite	Y N	0	1	2	3	4
Pain	Y N	0	1	2	3	4
Dry mouth	Y N	0	1	2	3	4
Weight Loss	Y N	0	1	2	3	4
Feeling drowsy	Y N	0	1	2	3	4
Shortness of breath	Y N	0	1	2	3	4
Constipation	Y N	0	1	2	3	4
Difficulty sleeping	Y N	0	1	2	3	4
Difficulty concentrating	Y N	0	1	2	3	4
Nausea	Y N	0	1	2	3	4

How frequently did these symptoms occur during the last week?

Symptom	Present	Rarely	Occasionally	Frequently	Almost constantly
Worrying	Y N	1	2	3	4
Feeling sad	Y N	1	2	3	4
Feeling nervous	Y N	1	2	3	4

References:
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Figure 48A.6 Continued

CHAPTER 49

Long-Term Care

Focus on Nursing Homes

Joan Carpenter and Mary Ersek

Key Points

- More than 25% of older adults and almost 70% of persons with advanced dementia live their final days in nursing homes.
- While the number of hospice patients living in nursing homes has increased dramatically over the past decade, other comprehensive palliative care models have not been widely adopted or tested in nursing homes.
- Hospice and palliative care nurses play critical roles in collaborating with nursing home staff to enhance end-of-life care and outcomes for older persons.

Introduction

Quality end-of-life (EOL) care in nursing homes is important. Over 1.4 million Americans live in nursing homes.[1] More than half of these nursing home residents require extensive assistance or are completely dependent in bathing, dressing, toileting, and mobility. Of those nursing home residents over 65 years of age, 80% are 75 years or older. Despite the efforts to keep frail elders in the community, the nursing home population is expected to increase as the numbers of older persons in the United States and other developed countries increase. Although nursing homes were not established as sites for EOL care, as more people live in nursing homes for short or long periods, they are increasingly becoming the place where many people die.

Long-Term Care

Long-term care refers to a continuum of services and supports addressing the health, personal care, and social service needs for persons who need help with activities of daily living (ADLs) as a result of cognitive, physical, or functional impairment.[2] Services may be provided in residential (nursing homes, assisted living facilities, residential care communities, group homes) or home and community settings (private homes, adult day service centers). About two-thirds of people receive long-term care services in residential settings despite efforts to increase long-term care in community settings.[3] Thus, the demand for high-quality nursing home care continues and is expected to increase with the aging population.

Non–Nursing-Home Residential Long-Term Care Settings

Assisted living facilities (ALFs) are residential settings that house people who need help coordinating day-to-day healthcare activities and supportive services but do not need 24-hour skilled nursing care. Services include meal preparation and planning, assistance with ADLs, medication monitoring and administration, and recreational activities.[4] State governments certify and regulate ALFs, and there is much variation among states with regard to regulations, definitions, and Medicaid support.[5] Residents and/or their families pay most expenses because there is relatively little state or federal government support for ALFs. After residing in assisted living for about 2 years, 60% of residents will move to a nursing facility for a higher level of care.[6] Increasingly, ALFs are becoming a setting of EOL care. ALF residents often report that they expect to die in this setting, and although ALF staff express confidence in caring for dying residents, they are unprepared to initiate EOL discussions.[7,8]

Continuing Care Retirement Communities (CCRCs) are for-profit or not-for-profit organizations that offer a full range of services including independent living, assisted living, and nursing home care. CCRCs provide different, as-needed levels of service in one location with a stepwise approach. For example, residents who experience physical or cognitive decline can receive additional ALF services, such as assistance with medications and ADLs. For short-term skilled care or longer term nursing care, a resident can move to the CCRC's nursing home. Most costs are paid out of pocket, and many facilities require that residents have Medicare coverage for skilled nursing care if and when needed.

Group homes (also called "adult family homes," "boarding homes," "personal care homes," and other names, depending on the state) are small dwellings where residents with similar needs live and receive help with ADLs. Residents in group homes do not need 24-hour skilled nursing care. These facilities are not as strictly regulated and often do not receive payments from Medicare or Medicaid programs.

Nursing Homes

There are almost 16,000 nursing homes in the United States.[1] All nursing homes provide 24-hour nursing care for residents. Many facilities provide short-term, rehabilitative care after hospitalization (i.e., skilled nursing care or post-acute care) and/or long-term care. Nursing homes that provide skilled care are often referred to as skilled nursing facilities (SNFs). SNFs can be stand-alone facilities, part of an acute care hospital, or facilities within a larger campus. The purpose of a SNF is to provide a place for residents to receive intensive medical and nursing care (e.g., giving intravenous fluids, changing dressings, administering tube feeding) and/or rehabilitation for a period of days to several weeks, with a goal of returning to a more independent level of activity. Following rehabilitation, residents are discharged home or admitted to another care setting for long-term care if they are unable to return home. For long-term care residents, the average length of stay in a nursing home is slightly more than 2 years.[9] However, the average length of stay for SNF decedents is 5 months.[10]

Nursing homes are not-for-profit, for-profit, or government facilities. Not-for-profit and for-profit facilities may be privately owned and operated by a single owner or part of a large organization with many facilities (e.g., a "chain"). Government facilities include about 132 Veterans Affairs (VA) nursing homes, referred to as Community Living Centers (CLCs).[11] State veterans homes are nursing facilities for veterans that are owned and managed by individual state governments.

In nongovernmental-run homes, there are three sources of payment: private pay (i.e., paid for using residents' financial assets or private long-term care insurance), Medicare, and Medicaid. Medicare pays for most short-term, skilled nursing care, while private pay and Medicaid covers most long-term nursing home care. Long-term care residents are often obliged to exhaust their life savings (i.e., "spending down") and then apply for Medicaid to cover costs associated with nursing home care. About two-thirds of older nursing home residents receive Medicaid benefits.[12]

From 2002 to 2012, Medicare spending for care in skilled nursing facilities grew by an average of 6% each year and is expected to increase through 2023.[12] The national median rate for skilled nursing home care in 2017 was between $7,000 and $8,000 per month. This is significantly more compared with the average monthly cost of care in an ALF ($3,750).[13] However, ALF care may be prohibitively expensive for residents and families since Medicare does not pay for these services and Medicaid coverage is limited and variable across states.[14]

History and Growth of Nursing Homes

Nursing homes have been described as the offspring of the almshouse and boarding house and the stepchild of the hospital.[15] In the mid-nineteenth century, older people who were poor, sick, or disabled and without family support had few options other than the alms-house. Private homes for the aged emerged as an alternative to public alms-houses after the passage of the Social Security Act in the 1930s.

The growth of nursing homes from the 1930s to the 1960s was related to several key factors. First, establishment of the Old Age Assistance (OAA) program in 1935 allowed some older adults to purchase long-term care services in private homes. Second, the Hill-Burton Act was amended in 1954, granting federal support for construction of public institutions, including those that housed older adults. Third, the American Association of Nursing Homes became a strong lobby for this new industry. With the creation of Medicare and Medicaid in 1965, the "nursing home" became fully established.[16]

The 1986 Institute of Medicine report, "Improving the Quality of Care in Nursing Homes," described many deficiencies in nursing home care and regulatory policies. In response, Congress passed the Omnibus Reconciliation Act of 1987 (OBRA-87). Contained in this bill was the Nursing Home Reform Act, which called for sweeping changes, including a focus on person-centered care and residents' quality of life (QOL).[17] In 1997, a large group of providers, regulators, researchers, and advocates formed the Pioneer network bringing together expertise, models, and other resources to promote this "culture change."[17]

The Affordable Care Act (ACA) of 2010 was the first legislation since OBRA-87 to address nursing home care quality and improve federal and state surveillance.[18] The ACA included transparency provisions allowing consumers to access information to help them choose a nursing home and monitor the quality of care (e.g., hours of nursing care that residents receive, consumer complaints, and staff turnover rates).[18] This information currently is available on the Nursing Home Compare website (www.medicare.gov/nursinghomecompare/). The ACA also incorporated a provision that nursing assistants receive training in dementia care and resident abuse prevention.

The Nursing Home Environment

Long-Term Care Residents

According to 2014 statistics, more than 80% of nursing home residents are aged 65 years or older and two-thirds are female.[1] More than 40% of residents need assistance with three of five ADLs (i.e., bed mobility, dressing, eating, mobility, or toileting), and 60% have moderate to severe cognitive impairment.[1]

Interdisciplinary Care Team

Nursing home staff and providers form an interdisciplinary team (IDT) consisting of medical staff, licensed nursing staff, certified nursing assistants, recreation therapists, and occupational and physical therapists. Other administrative staff (i.e., nursing home administrator, director of nursing) serve in leadership roles and oversee the daily operations in the facility. Dietary workers, environmental services personnel, and beauty shop employees also play important roles because they are part of the residents' home.

Nursing assistants, also called direct care workers, represent more than one-third of the staff in nursing homes; they provide personal care (e.g., bathing, dressing, grooming, toileting) and assist with ADLs.[19] Many nursing assistants have no formal education beyond high school, work for low pay, and receive few benefits.[20] Because nursing assistants spend the most time with residents, they often see more death and dying than other staff and experience the accompanying grief.[21] Despite their role in caring for dying residents, nursing assistants have the least amount of formal training in EOL care.

Licensed nursing staff include registered nurses (RNs) and licensed practical/vocational nurses (LPN/LVNs). They are responsible for administering medications, delivering treatments, assessing and managing physical and psychosocial problems, and communicating with primary care providers. RNs often manage and coordinate the overall care of residents and assume leadership positions, although the LPN/LVNs perform these duties when no RN is available. Compared with staff in the acute care setting, nursing home staff nurses are less likely to have baccalaureate or advanced degrees, and the less educated LPNs/LVNs generally outnumber the RNs.[22] These characteristics exacerbate the lack of palliative care knowledge and skills that have been documented among long-term care nursing staff.[23]

Nurse practitioners (NPs), physician assistants (PAs), and physicians provide primary care for nursing home residents. Since 2000, there has been considerable growth in NP and PA practice in nursing homes, although shortages of providers in nursing homes remain.[24] Between 2007 and 2014, the number of NPs and PAs who describe their practice as "skilled nursing facility specialists" doubled, and billable visits by NPs and PAs were greater than that of physicians.[25] Research demonstrates that greater NP/PA presence in nursing homes is associated with better nursing home care quality.[26]

Ethical Issues

Autonomy is based on the right of an individual to make decisions freely, including the right to accept or refuse a treatment. Nursing home routines, regulations, and restrictions result in an environment that is structured according to staff schedules, thereby hindering resident autonomy. Allowing residents choices, especially in directing their own care, is important. Nurses need to advocate for residents' autonomy.

One common and sometimes difficult ethical issue involves decisions about medically administered nutrition (i.e., tube feeding). Food in all societies is part of the ongoing cycle of daily interaction, and families may continue to try to feed their relatives when they are no longer able to eat. The use of feeding tubes to provide medically administered nutrition has not been shown to improve survival in individuals with end-stage dementia who are residing in nursing homes.[27]

Nursing home staff can assist families by explaining that it is normal to lose appetite or develop feeding difficulties at the end of life and that the body only takes in what it needs. Trying to force a resident to eat may cause more burden than benefit to the resident and increase distress for the caregiver. Nursing staff may encourage families to offer "comfort feeding" with small amounts of favorite foods and drinks. The goal of comfort feeding is to provide the most satisfying type of food during careful hand-feeding. Hand-feeding offers human interaction and therapeutic touch. Resources on the Choosing Wisely website (http://www.choosingwisely.org/patient-resources/feeding-tubes-for-people-with-alzheimers/) can help guide discussions with family members about feeding tubes and other treatments at end of life.[27]

Challenges and Opportunities for Palliative Care Delivery in Nursing Homes

Despite the benefits, implementing palliative care philosophy and approaches to care in nursing homes often is difficult. There are many barriers to delivering high-quality EOL care, although several characteristics facilitate the adoption of palliative care practices.[28]

Challenges to Palliative Care Delivery

Regulatory structures, reimbursement policies, workforce issues, and resident characteristics hamper the delivery of palliative care services in nursing homes. For example, regulations tend to favor restorative rather than palliative care.[29] In addition, efforts to administer palliative care are sometimes misinterpreted by facilities and regulators, leading to citations for poor care. For example, nursing home surveyors often cite facilities for residents' weight loss, which could reflect inattention to nutritional needs in some residents. In many instances, however, weight loss is an inevitable result of the dying process and aggressive interventions such as tube feeding are ineffective and inappropriate. Therefore, it is essential for interdisciplinary teams to document residents' life-limiting diagnoses, discuss care goals and preferences for life-sustaining treatments, and review and update the care plan accordingly.[30]

Reimbursement also promotes more aggressive therapy. Generally, Medicaid and Medicare pay nursing homes a per diem for the care they provide. Specifics of care are accounted for in the facility's *case mix index*, a composite score reflecting the complexity of care delivered to residents. In facilities providing more medical interventions, therapy services, and assistance with ADLs, the case mix index is higher, thereby increasing reimbursement rates to the nursing home. Therefore, facilities are financially incentivized to accept residents requiring "skilled" treatments. In addition, payment for a resident's room and board at the facility is generally covered under the Medicare SNF benefit for the first 20 days of care, following a qualifying hospitalization. Many seriously ill residents and their family caregivers find this financial assistance advantageous because out-of-pocket spending is reduced. These policies act as incentives to nursing homes to provide skilled nursing services and to residents and their family caregivers to accept them even though these services may not match the residents' and families' goals of care or improve residents' QOL.[28]

In addition to regulatory and financial pressures, workforce issues are challenging. Nursing home staff tends to lack training in palliative care approaches and therefore have difficulty recognizing and implementing palliative treatments when needed. Another workforce issue is staff turnover, which is staggeringly high. The annual turnover among nursing assistants is 52% and that of LPNs and RNs is 36% and 50%, respectively.[31] High turnover is associated with lack of care continuity and poorer care, resulting in a workforce that is constantly changing, overwhelmed, and dissatisfied. It also requires offering educational programs on a continual basis to keep knowledge and skills current.[28]

Until recently, there was little empirical research investigating the direct correlation between staff turnover and the ability of nursing home staff to deliver high-quality EOL care. However, one research team found significant associations between high staff turnover and residents' poorer quality of dying. They also found that family members believed that the lack of staff contributed to worse quality of dying for their loved one.[32]

Finally, many residents have complex physical and psychosocial needs that are difficult to assess and manage because of cognitive impairment.[1] Severe impairment interferes with residents' ability to provide reliable self-report, thereby hindering pain and symptom assessment and management. When pain and other symptoms are identified, multiple comorbidities and polypharmacy further complicate effective treatment.

Facilitators to Providing Palliative Care

Although there are hindrances, some nursing home characteristics facilitate palliative care delivery. These factors include daily interaction between direct care staff and residents, the existing team approach to care, family meetings, and use of the Minimum Data Set (MDS).[28]

Daily interaction between staff and residents who are familiar with each other establishes a rich context for developing relationships congruent with palliative care philosophy. Nursing home staff frequently describe themselves as part of the resident's family.[33] These close relationships can improve mutual understanding of residents' goals of care, values, and preferences, and result in better symptom management.

The existing IDT—RNs, LPNs, nursing assistants, social work, rehabilitation specialists, dietitian, and wound care specialists—also supports the palliative care philosophy. Nursing homes are required to schedule quarterly IDT care planning meetings with residents and/or their family members to discuss the comprehensive physical, emotional, mental, and social care plan for each resident. Care plan meetings provide a designated time that the IDT, resident, and/or family can review and share information; discuss values, goals, and treatment preferences; ask and answer questions; and revise the care plan to match the resident's needs.

The MDS is a mandated assessment tool for Medicare and Medicaid beneficiaries in nursing homes. Its goal is to create a comprehensive evaluation and to identify opportunities to improve functional status. The tool is completed by an RN at specified intervals using medical records, staff input, and observation in combination with a resident interview. The resident interview consists of discussions of preferences for routines and activities—including goals of care—and questions about pain, mood, and cognition.[34,35] The MDS can be used to identify residents with life-limiting illness who have unmet symptom management and psychospiritual support needs; these residents are candidates for palliative care.

Models to Deliver Palliative Care in Nursing Homes

There are three approaches to delivering palliative care in nursing homes: hospice-nursing home partnerships, external palliative care consultation teams, and in-house teams and specialized palliative care units.[28] Although these models have been operating for decades—for example, hospice services for nursing home residents have been Medicare-funded for almost three decades—there is limited evidence regarding their effectiveness in enhancing resident and family outcomes.

Hospice Care in Nursing Homes

Hospice care is the most common and well-established program for delivering palliative care in US nursing homes.[36] The Medicare Hospice Benefit (MHB) was extended to nursing homes in 1989, and, by 2004, 78% of nursing homes reported having at least one contract with a hospice agency.[37] In 2013, the Center for Medicare and Medicaid published requirements for nursing homes when they enter into a contract to provide hospice services to residents. One important regulation requires nursing homes that do not have a contract with a hospice agency to either (1) arrange for hospice services when appropriate or (2) assist with the resident's transfer to a facility that offers hospice if a resident chooses to use the MHB.[38]

The MHB pays for the hospice agency to oversee the plan of care and provide all medical supplies, IDT visits, and medications related to the terminal condition. The facility continues to deliver 24-hour nursing care for the resident. The MHB does not pay for room and board or for care focused on rehabilitation; as a result, hospice generally serves only long-term care residents and not those receiving care under the Medicare SNF benefit.[39,40]

The use of hospice in nursing homes is associated with improved symptom management, fewer hospitalizations, and increased satisfaction with care. Facility leadership report heavy dependence on formal agencies such as hospice to provide both palliative care to residents and palliative care education to their staff.[41] Research comparing EOL care for residents with and without hospice demonstrates that hospice care is associated with better psychosocial support, bereavement care, and pain management.[42,43] The challenge for hospice agencies, facilities, and providers is that many nursing home residents have a life-limiting illness with an uncertain trajectory, making it difficult to decide when the illness is "terminal" according to existing guidelines.[44] Hospices are required to discharge patients who no longer meet the MHB enrollment guidelines because they have either outlived their 6-month life expectancy or their health unexpectedly improves. For example, up to 14% of nursing home hospice residents with dementia are discharged from the MHB before death.[45] This raises serious concerns about the mismatch between the MHB guidelines and the illness trajectories of nursing home residents. Another challenge with hospice care occurs when there is poor communication and inadequate care coordination between nursing home and hospice staff. Bereaved family members report concerns about nursing home and hospice staff collaboration and communication. Two major concerns are delegation of patients' care tasks (e.g., who is responsible for what care) and information coordination (e.g., timely updates and sharing information).[46]

External Consultation Teams

An increasingly common and practical option for nursing home palliative care is external palliative care consultation teams who provide specialized services in nursing homes and make recommendations for the residents' care. Receipt of a nursing home palliative care consultation is associated with significant reductions in emergency room visits and hospitalizations, as well as fewer depressive symptoms.[47,48] Consultation teams often are an extension of a hospice agency's services, an existing hospital-based palliative care team, or independent practitioners. Depending on the team and resources, consultations focus on symptom management, advance care planning, or assisting with prognostication and/or hospice entry. Need for a consult is typically identified by staff and/or leadership, then formally requested by the primary care provider. The consultant bills for services under Medicare part B, and thus the costs for these services are not incurred by the nursing home.

The outcomes of external palliative care consultation depend on several factors. First, the consulting clinician needs to understand the nursing home environment and have knowledge of interventions that can and cannot be carried out. For example, the ability to administer and titrate intravenous opioids may be limited. Second, implementing recommendations depends on the nursing home medical provider being made aware of the consultant's clinical impression and his or her willingness to accept recommendations. Research has shown that miscommunication between hospital-based palliative care teams and nursing home providers and staff often result in a failure to implement recommendations.[49] Third, each nursing home has its unique culture. Depending on that culture, facility staff may feel EOL care is at odds with the philosophy of a restorative and rehabilitative model of care.[28]

Integrated Palliative Care

Over time, more facilities report that they provide internal palliative care services and train their staff in palliative care knowledge, practice, and skills. In 2016, one-third of nursing homes reported palliative care interdisciplinary rounds, 50% had instituted comfort-care policies, and 60% had instituted policies for palliative care.[36] Incorporating palliative care into daily routines requires a commitment to person-centered care and improving EOL care. Nursing homes that report higher palliative care knowledge and practice scores are associated with a lower likelihood of residents being exposed to burdensome treatments and transitions (e.g., artificial feeding tubes and emergency department visits).[50]

A major hindrance to developing internal nursing home palliative care services is the lack of funding and competing priorities. Baseline findings from a recently published randomized controlled trial entitled Improving Palliative Care through Teamwork (IMPACTT) suggests that the focus on SNF reimbursement and skilled care inhibits allocation of resources to facility-based palliative care.[51]

Another challenge to integrated palliative care is understanding what palliative care practices are practical and reasonable for nursing homes. In a recent Delphi study, researchers used national guidelines to identify preferred practices that were both important and potentially feasible to implement in nursing homes.[52] Additional work is needed to verify the usefulness of the findings because guidelines and recommendations, in and of themselves, are unlikely to change practice.

Specific Strategies for Enhancing Palliative Care

Some nursing homes incorporate specific palliative care approaches in addition to, or instead of, comprehensive models. These targeted areas often are pain and symptom assessment and management, advance care planning, and interventions to decrease hospitalizations.

Pain and other symptoms are common in nursing home residents. More than one-third of nursing home residents have intermittent or persistent pain.[53] Symptom assessment is particularly difficult in nursing home residents with advanced dementia due in part to their inability to communicate. Evidence from several studies show that, in people with dementia, pain and shortness of breath are the most common symptoms at the end of life and are challenging to control.[54–57]

Several intervention trials to improve pain management have been conducted. These studies used a variety of approaches, including quality improvement, pain management algorithms, specialized pain teams, and staff education.[15] The effectiveness of these approaches has been mixed.[58] Moreover, there are no high-quality trials of interventions aimed at non-pain symptoms.[15] Despite the lack of empirical evidence about effective ways to change pain and symptom management practices, many excellent resources are available to promote quality palliative care symptom assessment and management in nursing homes (Table 49.1).

Advance Care Planning

The number of nursing home residents with advance directives (ADs) increased dramatically since the PSDA was enacted.[59,60] When a resident lacks medical decision-making capacity, a resident's family member (acting as an appointed healthcare agent or surrogate decision-maker) will ideally use the AD as guidance when making decisions regarding medical treatments and EOL care. Most ADs for older nursing home residents reflect preferences for less aggressive EOL care. As a result, advance care planning and ADs are associated with decreased hospitalization rates, reduced antibiotic use, and increased likelihood of residents dying in the nursing home rather than the hospital.[60,61]

Although documented preferences about resuscitation are common, documented preferences about other interventions such as medically administered nutrition and hydration, hospitalization, antibiotics, and comfort measures are not.[62] The use of structured advance care planning interventions that result in portable life-sustaining treatment orders (i.e., POLST) is one way of encouraging discussion about, and documentation of, residents' and families' decisions about specific therapeutic approaches.[63] POLST programs increase concordance between residents'/families' preferences and care received.[64]

Despite the potential effectiveness of POLST, completing a POLST requires skilled, open discussion among clinicians, patients, and families. There is evidence that the quality of conversations is often less than ideal.[65–67] POLST forms can be difficult to interpret and explain. In addition, the amount of time advance care planning requires has been cited as a barrier to POLST form completion.[63,65,66] However, Hickman et al. demonstrated that a structured approach to discussions about care preferences that includes staff support and resource allocation increased advance care planning conversations and POLST form completion with a focus on preferences for less aggressive treatment.[63]

Decision aids can increase effective communication about values and goals at the end of life. Hanson and colleagues trained staff to use a goals-of-care intervention consisting of a video decision aid, along with a structured discussion guide for family decision-makers of nursing home residents with dementia.[68] Decision-makers reported better overall EOL communication and residents experienced less potentially burdensome transitions.

End-of-Life Transitions

Many nursing home residents are hospitalized in the final weeks of life[30,69] and receive burdensome treatments with little benefit and post-acute, rehabilitative-focused care.[39,49] EOL hospitalizations are costly and often avoidable.[26]

To address this problem, Ouslander et al. examined the effectiveness of several treatment algorithms and other tools designed to reduce hospitalizations.[70] Findings indicated that these tools can decrease hospitalization rates and healthcare costs. Packaged into a program, the Interventions to Reduce Acute Care Transfers (INTERACT)[71,72] tools were implemented in demonstration projects funded by the Center for Medicare and Medicaid Innovations (CMMI) (https://innovation.cms.gov/initiatives/rahnfr-phase-two/index.html).

Another promising approach to decreasing hospitalizations and promoting palliative care in nursing homes is the Optimizing Patient Transfers, Impacting Medical Quality, and Improving Symptoms: Transforming Institutional Care (OPTIMISTIC) project. This ongoing CMMI demonstration project is a multicomponent intervention aimed at improving medical care, managing care transitions, and supporting palliative care by placing specially trained registered nurses and nurse practitioners in nursing facilities. Findings show that the intervention reduces

Table 49.1 Palliative care resources for nursing home staff and other providers

Resource	Description
End-of-Life Nursing Education Consortium (ELNEC) Geriatric curriculum	Comprehensive training for nurses and nursing assistants, as well as social workers, chaplains, and others working in nursing homes. Also useful for hospice staff who serve nursing homes. ELNEC website: http://www.aacnnursing.org/ELNEC; Online training website: https://www.relias.com/elnec
Advancing Excellence in America's Nursing Homes	Initiative of the Advancing Excellence in Long-Term Care Collaborative; goal of the campaign is to ensure quality of care and quality of life for nursing home residents. Website contains resources on palliative care topics such as advance care planning and pain assessment and management organized within a quality improvement framework. Website: https://www.nhqualitycampaign.org/default.aspx
Core Curriculum for the Long-Term Care Nurse	Comprehensive curriculum in detailed outline, book format Organized by the National Consensus Project Domains.[77] Available from the Hospice and Palliative Nurses Association: https://www.hpna.org/HPNA_Item_Details.aspx?ItemNo=978-1-934654-30-9
Palliative Care in the Long-Term Care Setting	Developed for medical directors and primary care providers in nursing homes. Contains a variety of resources to improve palliative and end-of-life care through leadership, education, best-practice guidelines, and quality assurance. Available from the American Medical Directors Association: https://paltc.org/product-store/palliative-care-long-term-care-setting
Geriatric Pain Website	Website containing evidence-based materials to guide nurses and other nursing home staff in assessing and managing residents' pain, including those with dementia. Available at https://geriatricpain.org/
Palliative Care for Advanced Dementia	Developed by the Beatitudes Campus Dementia and Aging Research Department and Hospice of the Valley in Phoenix, Arizona, this interdisciplinary program specifically targets the knowledge and skills needed to provide person-centered comfort care to persons with dementia and their families. Available at http://www.comfortmatters.org/
Choosing Wisely website	Website includes clinician and patient/family resources to guide decision-making around several end-of-life issues for nursing home residents including: Feeding tubes: http://www.choosingwisely.org/patient-resources/feeding-tubes-for-people-with-alzheimers/ Hospitalizations: http://www.choosingwisely.org/clinician-lists/amda-aggressive-or-hospital-level-care-for-frail-elder/ Use of lipid-lowering medications: http://www.choosingwisely.org/clinician-lists/amda-lipid-lowering-medications/
Consult Geri_RN	Website with articles and videos relevant to the care of older adults, including pain assessment in nonverbal persons and avoiding restraint use. Available at https://consultgeri.org/
Palliative Care in the Nursing Home Setting[78]	National Hospice and Palliative Care Organization resource to guide collaboration between nursing homes and palliative care programs. Available at https://www.nhpco.org/sites/default/files/public/palliativecare/PALLIATIVECARE_PC_NursingHome.pdf
Nursing Home Palliative Care Toolkit[79]	Comprehensive toolkit developed by Healthcentric Advisors for long-term care facilities and stakeholders in Rhode Island. This 138-page guide contains nursing home-specific resources, assessment tools, and interventions. Available at http://healthcentricadvisors.org/wp-content/uploads/2015/01/nursing home-Palliative-Care-Toolkit_2014.pdf

potentially avoidable hospitalizations.[73,74] Furthermore, nursing home staff report that they find value in having access to specially trained project staff who can devote time to goals of care conversations and advance care planning discussions.[75]

Resources for Enhancing Palliative Care in Nursing Homes

Over the past several years, many professional and industry groups have developed curricula, websites, and other palliative care resources for nursing homes (Table 49.1). However, a recent systematic review revealed that education alone does not improve staff clinical practice and resident EOL outcomes.[76] Multifaceted programs that include education in addition to leadership support for EOL care processes and capacity-building for comprehensive palliative care delivery are more likely to be effective.

Conclusion

While nursing homes represent a unique short- and long-term care environment, modifications can help facilities in delivering high-quality EOL care. The nursing home staff should address the physical, psychological, social, and spiritual needs of all residents. Primary care clinicians need to recognize the regulations and guidelines under which facilities operate. Palliative care delivery models and targeted strategies can be integrated into nursing homes. The principles of palliative care should be an integral part of nursing home care.

Case Study: A Nursing Home Resident

Mr. X is an 87-year-old man with congestive heart failure, a pacemaker for sick sinus syndrome, and mild dementia. He was recently hospitalized with syncope related to anemia and diagnosed with myelodysplastic syndrome. Prior to the hospitalization, he lived in an assisted living facility and was able to care for himself. However, during the hospitalization, he experienced confusion, hallucinations, and significant functional decline. Mr. X was now receiving post-acute skilled nursing care and rehabilitation in a local nursing home. He was not making significant progress in physical therapy, slept a majority of the day, and had a poor appetite. On multiple occasions, he had told the nursing staff he was tired and wanted to be left alone. During the most recent MDS assessment, the staff noted his overall decline and worsening cognitive function and contacted the family to discuss his care. Mr. X's children were concerned that the new myelodysplastic syndrome diagnosis was causing his symptoms, and they wanted him to pursue "a little bit" of chemotherapy treatment "to see if it would help."

Mr. X clearly had many unmet needs. What was the first step? Could Mr. X make his own decisions? How would one know? What should one do now to ensure that Mr. X's goals of care are known? How should one document these goals in writing? How could palliative care help? What challenges could one anticipate? How could the nursing home staff support Mr. X? In what ways could the staff ensure that Mr. X's children are supported? Is hospice care appropriate? Why or why not? How could one ensure that Mr. X received treatments that matched his care preferences?

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CHAPTER 50

Palliative Care in the Community

Nancy Robertson and Barbara Sutton

Key Points

- The number of seriously ill homebound patients is increasing. The goals of care of this population reflect a desire for the quality of days to take precedence over the extension of life. Yet many end up cycling in and out of healthcare facilities and even dying in the hospital when their preference for death is to be at home.
- The number of unpaid caregivers is approximately 43.2 million. The estimated economic value of their unpaid contributions is approximately $470 billion. These caregivers are called upon to act as navigators and coordinators of an increasingly siloed and confusing healthcare system. There is an increasing understanding of the gap in care for this hidden, suffering population.
- Palliative care in the community is effective, decreases hospitalizations, and impacts positively symptom burden and caregiver distress. Individuals receiving community-based palliative care are more likely to complete advance care planning documents and to die at home.
- There is an urgent need for nursing education to prepare a qualified workforce to serve this population. Palliative care nurses at all levels must be trained, qualified, and competent to deliver high-quality palliative care to each suffering patient and family they touch.

Introduction

Informal palliative care has been delivered by nurses in the home for centuries. Managing symptoms, advocating for patient goals, and supporting caregivers are within the nurses' scope of practice as well as in their hearts. As the United States' healthcare system grew and became increasingly industrialized and siloed, these very important aspects of care have often been overlooked. Now that formalized palliative care is rising out of the arms of hospice and into its own specialty, nurses are positioned to impact positively the trajectory of patients and families as they face end-of-life (EOL) suffering.

Palliative care services are making great headway into the establishment of teams in the hospital settings. Among hospitals with more than 300 beds, more than 90% now have a palliative care team.[1] More recently, this specialty is expanding and migrating out from these hospital environments into the communities where people live and congregate. However, at this point, *community-based palliative care* services vary greatly in availability and standardization.

Background

Assuredly, medical advancements have had a positive impact on the human race. With the advent of hand-washing and sanitation, life expectancy has jumped 20–30 years. Add in major medical discoveries, such as penicillin and the development of state-of-the-art technologies, and it is now estimated that the average American will live to see 78.8 years of life.[2] Yet living longer presents challenges of its own. Currently, 45 million Americans are living with one or more chronic conditions that impact their function in a negative way.[3,4] This cohort accounts for 56% of all healthcare expenditures, an estimated $1 trillion.[3]

Of this highly complex population, almost 2 million are older adults who are homebound, while another 5.5 million are semi-homebound and requiring assistance from others to leave their homes.[5] These people face challenges of access to even the most basic healthcare and thus find themselves seeking much of their care through emergency services. They cycle in and out of hospitals and skilled nursing facilities. This fragmented care and multiple chronic conditions cause them to become the costliest patients in the US healthcare system.[6]

The goals of this population reflect a desire for the quality of days to take precedence over the extension of life.[7] In addition, greater than 80% of Medicare beneficiaries aged 65 years and older want to die at home. Yet, in 2013, one-third of the 1,904,640 deaths among patients of this cohort occurred in the hospital.[8] As this population experiences the advances of serious disease, family members are pressed into caregiving roles. This is creating a crisis of a proportion previously unknown in the United States. As the baby boom generation (those born between 1946 and 1964) grows older, a substantial shift in the age composition of the US population is taking place. By 2029, more than 20% of the US population will be over 65 years of age.[9] With advanced age comes increased debility, need for assistance, and caregiving.[10]

Caregiver Crisis

Family caregivers have historically been the mainstay of care in the home for ill members of the family. Today, this care has morphed into a highly complex, stressful, and costly burden. Caregivers are now called upon to act as navigators and coordinators of an increasingly siloed and confusing healthcare system. They find themselves monitoring chronic conditions as well as acute illnesses as hospitals are discharging patients who are sicker and less prepared to leave the arms of the 24-hour professional staff.[11]

In 2014, an estimated 43.2 million adults provided unpaid care to an adult living with serious disease.[12] They performed assistance with all activities of daily living including shopping, transportation, managing finances, and meal preparation as well as bathing and dressing. More than half performed nursing duties such as managing medical equipment, handling incontinence, caring for wounds, and overseeing the administration of medications.[11] These caregivers reported an average of 24.4 hours a week spent providing care to their loved ones. Sixty percent of family caregivers were employed either full-time or part-time. Of those working caregivers, 40% were aged 50 years and older.[12]

Caregivers increasingly suffer from anxiety, depression, compassion fatigue, and burnout.[13,14] More than half of all caregivers work full-time, and six in ten report at least one impact or change to their job situations as a result of caregiving, such as being admonished for a poor performance or attendance or needing to take a leave of absence. Four of ten caregivers report high stress, and 38% report increased financial stress. More than half report that caregiving has negatively impacted their job performance.[13]

Caregivers also experience a high incidence of physical problems, including an increase in heart disease, hypertension, stroke, poorer immune function, sleep problems and fatigue, and even death among highly stressed spouse caregivers.[13,15–17] Caring for a loved one with dementia is particularly stressful, with the added burden of experiencing all of the preceding conditions as well as social isolation, visits to the emergency department, or hospitalizations.[12,18]

The estimated economic value of unpaid contributions in caregiving was approximately $470 billion in 2013, up from an estimated $450 billion in 2009.[12] Additionally, 9.7 billion in healthcare dollars are spent on caregivers themselves due to the physical and emotional toll caregiving takes.[19]

Palliative care in the community has the capability to answer many of the challenges currently being faced by patients with serious illness and the families who are struggling to care for them. Impact of community-based palliative care programs has demonstrated improved caregiver burden and a better maintenance of caregiver quality of life and family satisfaction.[20]

Palliative care services, utilizing the interdisciplinary team (IDT) model, can assess and intervene with symptom burden, identify and work to decrease caregiver burden, coordinate appropriate community resources, establish goals of care and treatment preferences, coordinate care, and assist in providing a badly needed and critical layer of support.

Effectiveness of Palliative Care in the Home

Though more research is needed to validate the effectiveness of the palliative care community-based programs, the preliminary evidence is highly encouraging. Enhanced symptom management, improved patient quality of life, reduced aggressive care at the end of life, increased advance directive completion, reduction in hospitalization rates and emergency room visits, and decreased days in the intensive care unit (ICU), as well as improvement in patient and family satisfaction scores is seen in observational data and evidence from randomized trials.[3,20–22]

A 2016 Cochrane review revealed strong evidence that home palliative care increases the chances of one dying at home if that is the desire. Home palliative care was also found to reduce symptom burden, in particular for patients with cancer, without impacting the grief experienced by the caregiver.[23] What is even more intriguing are the results found by Dr. Higginson and colleagues in a small randomized trial conducted in 2013. These researchers questioned the effectiveness of integrating palliative care early in the disease trajectory of patients with advanced disease and refractory breathlessness. Fifty-three of the participants were randomized to a breathlessness support service, while fifty-two received usual care. Their results strongly support the early integration of palliative care for patients with diseases other than cancer and breathlessness, as well as for those with cancer. In addition, they found a statistically significant longer survival rate for patients with chronic obstructive pulmonary disease and interstitial lung disease in those patients receiving palliative care in community settings as compared with others with the same diagnosis but not receiving this specialized care.[24]

Delivery Models of Community-Based Palliative Care

As of 2017, there existed no standardized approved delivery models for community-based palliative care services. Most of the current models of community-based palliative care are driven by reimbursement and finances. As the majority of the disciplines that serve on a palliative care team are not covered under current payment structures, hiring a full complement of staff is extremely difficult. Social workers, chaplains, care coordinators, and all nurses not licensed as advance practitioners are not eligible for reimbursement. This leaves only licensed clinical social workers (LCSW), advance practice registered nurses (APRN), physician assistants (PA) and physicians as being able to bill. As APRNs receive 85% of the physician fee schedule, this further reduces the ability to generate income.

Community-based palliative care practices must be smart and creative to keep their doors open. Some may, for example, decide to focus their geographical catchment in order to minimize expensive drive time for their staff. Practices may see patients in certain zip codes limit their services to specific facilities such as independent living facilities (ILFs), assisted living facilities (ALFs), skilled nursing facilities (SNFs), or senior communities. A short description of various models follows.

Consultative Programs

Consultative community-based palliative care programs work with primary care providers. Their staff assesses seriously ill patients and families then makes recommendations to the primary care team to meet the identified palliative care needs. The OACIS Lehigh Valley Health Network is one such example. OACIS utilizes palliative care-trained APRNs and RNs to work closely with primary care providers, often using telehealth, home visits, and 24/7 access. The community-based palliative care staff functions as a consultant service and does not provide primary care.

Home Health

Home healthcare agencies (HHC) may provide primary palliative care in order to meet the needs of their medically complex patients who may not yet be eligible for hospice or whose goals of care do not reflect the hospice philosophy. Home healthcare agencies are primarily reimbursed through Medicare A, Medicaid, and commercial insurances for episodic care for nursing or therapy needs. Patients must meet criteria for home healthcare and must demonstrate progression toward improvement. RNs are reimbursed within the per diem rate, whereas APRNs may bill for their palliative care services under Medicare B, Medicaid, or commercial insurances per visit. Patient and referral source satisfaction lead to increased referrals for the HHC agency, increasing revenue, and support of the community-based palliative care practice.

Hospice

Community-based palliative care may be provided by hospice agencies as a separate service line. For patients who are not currently eligible for the hospice benefit or who are continuing to seek curative or life-prolonging treatment, the hospice agency's palliative care service will deploy APRNs, RNs, and occasionally social workers and chaplains to render these services. APRNs and LCSWs bill under Medicare B, Medicaid, or commercial insurance, although fee-for-service billing is rarely adequate for a sustainable practice. The hospice agency justifies this service arm by metrics such as earlier referrals to hospice, improvement in quality care, and increased length of hospice stays.

Private Duty Nursing Agencies

Private duty nursing agencies may offer palliative care provided by certified nursing assistants (CNAs) and RNs, primarily in support of the plan of care developed by palliative care specialists. Payment is through long-term care insurance or as an out-of-pocket expense.

Primary Care Practices

Primary care practice in the home is a growing field that is providing care to people with multiple medical morbidities and complex illness right where they live. There is no medical specialty more appropriately positioned to deliver palliative care than those practicing in the general practice setting. They know the medical, psychosocial, and environmental challenges faced by their patients better than any other provider. As such, general practice APRNs are seeing the demand for addressing palliative care during their home-based primary care visits. Most community-based primary care programs are reimbursed by Medicare B, Medicaid, and commercial insurance. They are often available 24/7. Home-based primary care programs vary widely from the multistate VA system, which utilizes the MD/APRN model, to solo APRNs making house calls.

Independence at Home (IAH) Demonstration is a Medicare Innovation Model providing home-based primary care through programs led by nurse practitioners or physicians. IAH has shown substantial savings in overall care of enrolled patients, as well as fewer hospitalizations and emergency room visits.

Within this construct, those primary care providers who are palliative care–trained make a valuable impact to meeting the palliative care needs of their seriously ill patients. However, their approach is somewhat "grass roots" at this moment. Primary care providers who have advanced their palliative care skills and knowledge are able to identify and address palliative care needs, but the approach is reactive in nature. As this area matures, ways to incorporate the identification and treatment of palliative care needs from a systematic viewpoint will emerge.

Free-Standing Palliative Care

There are palliative care programs that exist without attachment to other service lines. These exist in those hospital systems that often wish to impact negative metrics such as the 30-day rehospitalization metric. Various forms of teams consisting of nurses, social workers, and administration staff work to provide palliative care to their patients after discharge from their hospital setting. Their reimbursement is in the form of fee-for-service billing (if they have clinicians with licensure to bill) or by avoiding the penalties associated with frequent readmission rates.

Another version of the free-standing palliative care model is profit, multistate organizations. These companies are reimbursed by insurances on a per-patient per-month basis. The goal is to reduce the hospitalizations and increase hospice referrals for enrollees with high utilization rates. These patients are often defined through an algorithm using data held by the insurance company. APRNs and RNs work in tandem with a physician to manage symptoms, provide education and support, and discuss goals of care and advance care planning.

Pediatric Palliative Care

Pediatric palliative care in the community is complex. Children covered by state Medicaid or Children's Health Insurance Program (CHIPs) and who have a terminal illness are able to receive hospice care and curative therapies simultaneously. A child may be eligible to receive skilled intermittent and 24-hour nursing along with respite care and other therapies. There are few pediatric community care programs in the United States due to cost and payment limits.

Rural Palliative Care

The use of telemedicine in providing palliative care in the community is more common in remote areas. An office-based RN monitors the telemedicine units for changes in patient condition or symptoms and dispatches the appropriate service, which could be in the form of a phone call or a physical or virtual visit. Resolution Care in Eureka and Mendocino, California, is one such example. This delivery model has been found to reduce ED visits and to increase satisfaction and referral to hospice.[25–27]

Payment for Palliative Care Services in the Community

Reimbursement for palliative care in the community is in a state of flux. As the traditional model of paying for services rendered is moved to value-based payment structures, there is increased opportunity for community-based palliative care. Moving to value-based and risk-sharing partnerships may allow the hiring of a full complement of IDTs and allow the right kind of care to be delivered to the right kind of patient at the right time.

The traditional fee-for-service billing incorporates ICD-10 codes and Current Procedural Terminology (CPT) codes. Please see Table 50.1 for the most common palliative care ICD-10 codes currently being utilized and Table 50.2 for CPT codes.

Delivering palliative care services often entails more time than most other medical services. It is imperative that the community-based palliative care teams understand how to bill for palliative

Table 50.1 Commonly used International Classification of Disease (ICD-10) codes for palliative care

Diagnosis	ICD-10
Palliative care encounter	Z51.5
Anxiety disorder, unspecified	F41.9
Depression, major, single episode, mild	F32.0
Depression, major, single, moderate	F32.1
	********************************
Altered mental state	R41.82
Anhedonia	R45.84
Anorexia	R63.0
Aphasia	R47.01
Apnea	R06.81
Ataxia	R27.0s
Agitation	R45.1
Abdominal distention	R14.0
Constipation	K59.00
Cough	R05
Circadian rhythm sleep disorder, unspecified	G47.20
Diarrhea, unspecified	R19.7
Difficulty walking	R26.2
Dizziness	R42
Dry mouth, unspecified	R68.2
Dysphagia	R13.10
Dyspnea	R 06.0
Delirium/confusion	R41.0
Early satiety	R68.81
Edema, localized	R60.0
Edema, generalized	R60.1
Fatigue, general	R53.83
Fatigue related to neoplasm (malignant)	R53.0
Fever, unspecified	R50.9
Fever, drug induced	R50.2
Flatulence	R14.3
Gas pain	R14.1
Gait, ataxic	R26.0
Gait, paralytic	R26.1
Other abnormalities of gait and mobility	R26.89
Unspecified abnormalities of gait and mobility	R26.9
Hallucinations, unspecified	R44.3
Headache	R51
Hypoxia	R09.02
Incontinence, feces	R15.9
Incontinence, urine	R32
Insomnia	G47.00
Itching/pruritis, unspecified	L29.9
Malnutrition, unspecified protein calorie	E46
Malnutrition	E43
Malaise	R53.81
Nausea	R11.0
Nausea and vomiting	R11.2
Neuropathy, unspecified	G62.9
Nocturia	R35.1
Pain, abdomen	R10.9
Pain, generalized	R52
Pain, chest	R07.1
Pain, related to neoplasm	G89.3
Pain, headache	R51
Pain in unspecified limb	M79.609
Pain, low back	M54.5
Pain in muscles/myalgia	M79.1
Pain, neck	M54.2
Paresthesia	R20.2
Sepsis, unspecified	A41.9
Shortness of breath	R06.02
Somnolence	R40.0
Stupor	R40.1
Tachypnea	R06.82
Tremor, unspecified	R25.1
Unspecified abnormal involuntary movements	R25.9
Underweight	R63.6
Urinary frequency	R35.0
Vomiting, unspecified	R11.10
Weight gain, abnormal	R63.5
Weight loss, abnormal	R63.4
Weakness, generalized	R53.1
Goals of care	Z71.89

care services based on time. To utilize time-based billing, the APRN must spend the entire allotted time face-to-face with the patient in the home. Any coordination of care done away from the patient is not billable. When billing is based on time, there are no specific documentation requirements for history, physical exam, and medical decision-making. The APRN must record the duration of the encounter on the record and also state that more

Table 50.2 Current Procedural Terminology (CPT) codes for home and assisted living facilities

Home visits	CPT codes
New Pt – Initial Home visit – typical time 20 minutes to complete	99341
New Pt – Initial Home visit – typical time 30 minutes to complete	99342
New Pt – Initial Home visit – typical time 45 minutes to complete	99343
New Pt – Initial Home visit – typical time 60 minutes to complete	99344
New Pt – Initial Home visit – typical time 75 minutes to complete	99345
Established Pt – F/U visit – typical time 15 minutes to complete	99347
Established Pt – F/U visit – typical time 25 minutes to complete	99348
Established Pt – F/U visit – typical time 40 minutes to complete	99349
Established Pt – F/U visit – typical time 60 minutes to complete	99350
Assisted-living facility visits	**CPT codes**
New Pt – Initial visit – typical time 20 minutes to complete	99324
New Pt – Initial visit – typical time 30 minutes to complete	99325
New Pt – Initial visit – typical time 45 minutes to complete	99326
New Pt – Initial visit – typical time 60 minutes to complete	99327
New Pt – Initial visit – typical time 75 minutes to complete	99328
Established Pt – F/U visit – typical time 15 minutes to complete	99334
Established Pt – F/U visit – typical time 25 minutes to complete	99335
Established Pt – F/U visit – typical time 40 minutes to complete	99336
Established Pt – F/U visit – typical time 60 minutes to complete	99337
Nursing-home visits	**CPT codes**
New assessment – Initial visit – typical time 25 minutes to complete	99304
New assessment – Initial visit – typical time 35 minutes to complete	99305
New assessment – Initial visit – typical time 45 minutes to complete	99306
Subsequent visit – typical time 10 minutes to complete	99307
Subsequent visit – typical time 15 minutes to complete	99308
Subsequent visit – typical time 25 minutes to complete	99309
Subsequent visit – typical time 35 minutes to complete	99310

Use prolonged codes 99354 and 99355 if the visit goes over the typical time requirement and meets the threshold of time for these prolonged codes.

than half of that time was spent on counseling and coordination of care. New advance care planning codes were released by Medicare in January 2017. Though the reimbursement rate is relatively low, there is value.

Value-based billing made up 38% of all US healthcare payments at the end of 2015.[28] Tightly woven into the value-based payment structures is the need to identify, collect, analyze, and report on measurements and metrics of the palliative care programs. Measuring the quality of care delivery is integral to hospice and palliative care programs, as specified by the National Consensus Project (NCP) Clinical Practice Guidelines and the Joint Commission Advanced Certification Program for Palliative Care, as well as by stakeholders and payers.[29,30] Currently, no national standards for measurement or databases that would support benchmarking exist in palliative care.

The Quality and Practice Standards Committee of the American Academy of Hospice and Palliative Medicine (AAHPM) along with the Hospice and Palliative Nurses Association (HPNA) initiated the Measuring What Matters (MWM) consensus project. The overall goal of the project was to recommend a concise portfolio of valid, clinically relevant, cross-cutting performance indicators for internal measurement for hospice and palliative care programs.[31]

Roles and Responsibilities of the Specialized Palliative Care Team in the Community

There is much discussion in healthcare literature about how healthcare disciplines, operating in numerous silos, interact to care for patients. The traditional model of multidisciplinary teams incorporates the hierarchical structure with physicians typically carrying the full weight of the ultimate responsibilities for the decisions made by the team. Each member on this traditional team has clearly identified roles and responsibilities. They contribute to the overall care of the patient in relative isolation from the others on the team.

In palliative care, however, this approach is less than ideal as the patient and the family are the ultimate decision-makers for the plan of care. To advocate, honor, and respect individuals' choices, the interdisciplinary approach is much more applicable. IDTs base their function as a team on interdependent interaction, which results in a synergistic effect that happens when the members possessing specific expertise work closely together.[32]

The IDT grows to understand each other's disciplines, expertise, and opinions. They learn from each other and add to their skill set with tools learned from their colleagues. This allows team members to support and cover for each other to an extent they could never do before.

Many teams in the community do not have complete coverage by all disciplines. The majority of palliative care teams in the community are primarily made up of care coordinators, caregivers, nurses, and social workers, though for completeness, other disciplines do participate in community-based palliative care IDTs. Please refer to Table 50.3 for roles and responsibilities of the disciplines typically found on a palliative care team.

Table 50.3 Roles of palliative care interdisciplinary team (IDT) members

Caregivers	Provide daily or around-the-clock custodial care. Often family members or may be paid professionals
Registered nurses/ licensed practical nurses (RNs/LPNs)	Deliver skilled care as directed by care plan
Advanced practice registered nurses/ physician assistants (APRNs/PAs)	Coordinate total patient care to complex patients; supervise/delegate to other nurses; assess and diagnose; prescribe medications
Physical therapists	Deliver skilled care to increase strength and function, assess for assistive devices
Psychologists	Address stress, body image, depression
Occupational therapists	Address patients' abilities to perform their everyday tasks with greater independence and efficiency.
Speech therapists	Improve speech and swallowing problems, address hearing loss, language problems
Chaplains	Address spiritual issues, adjustment to "new normal"
Physicians	Coordinate/oversee nursing and therapists staff, certifies care plan
Nutritionists	Provide diet counseling for special nutritional needs
Pharmacists	Review medications, make recommendations for adjustments, cost, contraindications
Volunteers	Assist patients and families in meeting goals, legacy work, socialization
Home health aids	Perform personal care and basic nursing tasks
Homemakers	Provide cleaning, tidying, shopping, pet care
Social workers (MSW/LCSW)	Identify needs of family and patient, refer to community resources, counselling

Rules and Regulations of Palliative Care Nursing in the Community

State regulations, Medicare, and commercial insurance companies each impact the practice of community-based palliative care nursing. State nurse practice acts vary widely in the scope of practice for RNs and APRNs. It is recommended that nurses familiarize themselves with the state regulations guiding their practice. The National Council of State Boards of Nursing provides resources and can be found at https://www.ncsbn.org/nurse-practice-act.htm.

Guidelines for community-based palliative care are generally similar to those for home-based primary care. Medicare does not require patients to be homebound as long as the justification is documented and the visit is not for convenience or at the patient's request.[33]

Academic Requirements for Community-Based Palliative Care Nurses

Palliative care, as its own area of expertise, has grown significantly since the American Board of Medical Specialties approved the creation of hospice and palliative medicine as a subspecialty in 2006. This approach to care is so new that generations of healthcare professionals have had no exposure to it. This presents a significant challenge to palliative care academia to keep up with the demand for quality curriculum and programs to educate its clinicians. In 2000, the End-of-Life Nursing Education Consortium (ELNEC) project was funded by The Robert Wood Johnson Foundation. This national education initiative to improve palliative care developed and delivers nursing curriculum in EOL care. This project has been extremely successful in impacting the knowledge curve for all nurses' caring for patients living with serious illness. In 2013, ELNEC debuted its curriculum for the APRN community. The ELNEC website states that it has trained "over 21,400 nurses and other healthcare professionals, representing all 50 US states, plus 90 countries."[34]

Outside of this highly contributive body of work, the availability of accredited programs is few and at present remains small. In 2017, the Hospice and Palliative Care Nursing Association's website listed 15 master's and doctoral palliative care graduate programs available and another three with electives in Palliative Care.[35] Two newly created, innovative programs launched at the University of Colorado and another at the University of Maryland offer interprofessional master's degrees and certifications in palliative care. These programs incorporate students and faculty from all palliative care disciplines.

Although these novel programs and others segregated by discipline are currently developing, schools will require years to graduate the estimated 10,000 educated clinicians this field requires.

While the opening of community-based palliative care programs is hailed as filling a rapidly growing need, there is currently a dearth of trained, qualified, palliative care professionals. As the understanding and acceptance of specialty palliative care is increasingly understood and embraced, the appreciation for integrating palliative care earlier in the disease trajectory creates an exploding demand for these nurses and other healthcare professionals.

Community-based agencies struggling to meet the demands of increased referrals have no other choice but to recruit and hire untrained, unqualified clinicians.

The Institute of Medicine "Dying in America" report released on September 17, 2014, draws attention to this serious problem. As a result of this committee's exhaustive work analyzing the current state of EOL care in the United States, their third recommendation calls upon academic institutions, national and state accrediting bodies, and healthcare delivery organizations to assure appropriate training and certification for all clinicians who care for patients and families living with serious illness.[4]

Fortunately, leading national palliative care organizations anticipated this need years ago and have published guiding principles for the education of future practitioners. The National Consensus Project for Quality Palliative Care, a subcommittee of the Hospice and Palliative Care Coalition, is one such organization. This project drew upon five major US palliative care organizations to develop clinical guidelines for quality palliative care services. The guidelines, originally released in 2004, have undergone two revisions and are now in their fourth, released in 2018.

Specifically for the nursing discipline, the Hospice and Palliative Care Nurses Association established standards of care in their important document "HPNA Standards for Clinical Education of

Hospice and Palliative Nurses," originally created in 2005, with their second edition released in 2015.[36]

The Joint Commission, a national accrediting body, launched their certification program for hospital-based palliative care in 2011, closely followed with their certification for community-based palliative care programs in 2016. The Joint Commission requires that clinicians are trained in palliative care.

The Center to Advance Palliative Care (CAPC) is a national organization that has created an in-depth platform of education, mentoring, tools, training, and measurements. These can be found at the Center to Advance Palliative Care website www.capc.org.

Since 1965, Community Health Accreditation Partners (CHAP) has been working to elevate and standardize care delivered in the community. In 1992, CHAP began a relationship with Centers for Medicare and Medicaid Services; compliance with CHAP standards can be used by organizations to demonstrate that they meet the conditions of participation for home health, hospice, and HME Medicare/Medicaid programs.

The establishment of these curricula and position statements is a critical step. Moving to an accepted standard for entry-level palliative care clinicians is the next. It is imperative that agencies ensure that their palliative care clinicians are adequately educated, trained, and supported, as well as having appropriate certification.

Community-based Palliative Care Summary

The United States is struggling under the burden of an overpriced, procedurally driven healthcare system that minimizes patient autonomy and self-determination. The growth of palliative care is one answer to redirecting the course. Great headway has been made in the hospital system and is now evolving to impact other healthcare settings. Delivering the right service to the right patient at the right time is essential. Providing services to the home where patients and their struggling caregivers live is the next phase, and it has begun. Models of delivery are as individual at this point as there are agencies to deliver these services. But national projects are under way to develop a consensus as to what these services should entail and the payment structures needed to sustain these services.

What is very clear is that palliative care services need to be delivered by multiple disciplines in multiple settings. Blending these disciplines into one efficiently running IDT and delivering this approach wherever patients and families live holds great promise to answering many of the healthcare struggles the US currently faces.

> I had a good friend who died from brain cancer. She was 63 years old. I gave her a copy of "Being Mortal" and talked to her about hospice 6 months before her death. Her doctor kept encouraging her to try to get accepted into experimental treatment trials. She finally referred her to hospice 10 days before she died. I was so angry! I am not a medical professional, but I do know that people do not recover from glioblastoma tumors. I also know that palliative care could have made the last several months of her life so much easier for her and her family. (Written permission given by Elaine Sanchez to share with readers of this textbook)

The Future for Nurses in Palliative Care in the Community

Nurses have been bringing care, including unnamed palliative care, into people's homes since the 1800s. The current move of healthcare back into the community brings with it the opportunity for nursing to continue to positively impact the trajectory of patients' and families' experience of serious illness. Through exemplary communication skills and a wide-ranging knowledge base, the nursing force is set to deliver multifaceted care while acting as liaisons and guides for seriously ill patients attempting to navigate the increasingly complex healthcare system. Nurses, with their ability to respond quickly to changing patient needs, fulfill the large unaddressed gap in care. By effectively orchestrating much-needed difficult conversations around advance care planning, managing immense symptom burden, intervening with caregiver strain, and coordinating care, nurses impact the very heart of suffering.

Now, more than ever, the need is great for nurses from all backgrounds of healthcare to seek out and obtain advanced education in palliative care. Identifying patient wishes and goals of care along with treatment preferences, then advocating for these desires, is one of the true callings of the nursing discipline. Our discipline must be trained, qualified, and competent to deliver high-quality palliative care to each suffering patient and family we touch.

Case Study: A Patient in Palliative Care

Agnes is an 84-year-old woman with hypertension, chronic kidney disease, atrial fibrillation, congestive heart failure (CHF), dementia, recurrent urinary tract infections (UTIs), falls, and arthritis in her knees and hips. She was hospitalized a year ago for a CHF exacerbation. During that hospitalization, she and her daughter, Gina, met with the palliative care team. Together they helped Agnes define her goals of care. She wanted to be home, avoid all hospitalizations if possible, and not be a burden to her daughter. Agnes felt she had lived a long and happy life, and, when it was her time, she was ready to go.

Upon discharge, Agnes was referred to a home health agency with a palliative care practice. At the palliative care APRN's first visit, she found Agnes weak, fatigued, and at high risk for falls. Agnes was taking Lisinopril, memantine, furosemide, potassium, warfarin, donepezil, atenolol, trimethoprim-sulfamethoxazole, acetaminophen, omeprazole, and atorvastatin. These medications cost $750 out of pocket each month.

The rest of the admission exam revealed a blood pressure (BP) of 104/60, weakness, a chronic cough, and a pain rating of 6/10 in her knees on most days, which is aggravated with walking. The APRN's assessment of Agnes's chronic cough, hypotension, and weakness led her to stopping the angiotensin converting enzyme inhibitor (ACEI). Following this one change, Agnes's blood pressure rose, the ACEI cough stopped, and the daily pill burden decreased.

Gina had been giving her Mom acetaminophen only when she asked for it, about once every other day. The APRN taught Gina about pain management and the necessity of assessing the pain often, as well as the treatment plan and asked her to keep a pain diary to be reviewed on each visit.

Working with the primary care team as well as with Gina and Agnes, the palliative care APRN outlined the benefits and risks of all Agnes's medications. Collaboratively, it was decided to stop the omeprazole and taper down the donepezil and memantine. Gina felt strongly that she wanted her Mom to continue the trimethoprim-sulfamethoxazole as Agnes's last UTI was a rough event, but she did question the need for the warfarin with all its needs for laboratory monitoring. Her cardiology team authorized stopping both the atorvastatin and the warfarin but, with Agnes's atrial fibrillation, recommended a daily 81 mg ASA in the warfarin's place. A trial of lowered dosing of the furosemide and potassium was conducted. The BP remained below 120 systolic and no edema presented. Eventually, these two medications were stopped as well. The pill burden decreased to four pills and a zero out-of-pocket expense.

Building on the goals of care conversations started in the hospital, the APRN talked with Gina about the benefits of hospice. This early discussion, before Agnes was eligible for the hospice benefit, allowed Gina to consider the option while there was no crisis or urgency. When the topic of a feeding tube was brought up to address Agnes's continued weight loss, Gina asked the APRN about it. She was relieved to find out that it was not recommended for older adults with dementia and that she would not be in "trouble" if she does not have one inserted.

Agnes felt better than she had for a long time with only four pills, twice weekly visits from her RN, and every-other-week visits from the APRN. Scheduling the acetaminophen had decreased her pain, as exhibited by her active participation in activities, no acting out, and no grimacing when she was assisted in moving. During one of the home health visits, Gina shared with the RN that she continued to feel completely overwhelmed, despite the current support. Gina had called in sick to work three times since her Mom had been home, and she worried this would impact her job performance. The RN notified the home health licensed clinical social worker (LCSW) who began working to impact the caregiver strain Gina was experiencing.

Agnes's condition stabilized. With no more skilled needs, the home health agency discharged her from their services. Fortunately, as the palliative care team did not have the insurance restrictions imposed on them as the home health agency did, Agnes and Gina continued to be supported by their palliative care providers.

Over the next several months, Agnes became less verbal, unwilling to walk even short distances, refused to take her medications, and was incontinent of her bowels and bladder. She rarely smiled at her daughter. By her 85th birthday, Agnes was completely homebound. Though Agnes was no longer able to get out to see her primary care provider (PCP), the palliative care APRN continued to visit in the home and medically managed her conditions by working collaboratively with her PCP team. With a FAST scale of a 7c, Agnes was now eligible for her hospice insurance benefit. As the team had spoken numerous times with Gina as the disease progressed, she was fully on board with this transition. The same APRN who worked on the palliative care team also worked as the hospice attending, and she accepted Gina's request to assume her Mom's care.

With the hospice benefit, a full array of team members came to care for Agnes and Gina. Another month went by and Agnes's function continued to decrease. Now Agnes rarely got out of bed. Two weeks later, Agnes died with Gina sitting by her side, holding her hand.

Case Study Summation

This case study illustrates what the early integration of palliative care in the disease trajectory can do. In this example, three hospitalizations were avoided: one sub-acute stay and one nursing home admission. Pain was identified and aggressively treated from the start, allowing Agnes to enjoy her days. Agnes did not have a feeding tube inserted. The caregiver stress, burden, and grief were positively impacted. Hospice was accessed sooner, bringing with it substantial aid and support to the situation.

Perhaps the most important illustration that the case study with palliative care provides is that Agnes's goals of care and treatment preferences were identified, advocated for, and honored. She received the kind of excellent medical care she wanted from the beginning of her serious illness until she passed away in the place she requested and in the presence of her loved one.

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CHAPTER 51

The Intensive Care Unit

Jennifer L. McAdam and Céline Gélinas

Key Points

- All intensive care unit patients deserve palliative care, whether the goal is cure or a peaceful end of life.
- Although an ICU is rarely the place where patients would choose to die, transition from aggressive care to end-of-life care is a frequent occurrence.
- Optimal transitional care in ICUs requires clear communication among patients, families, and care providers from multiple disciplines.
- The appropriateness of procedures should be assessed, unnecessary procedures eliminated, and the pain associated with necessary procedures treated appropriately.
- Analgesics should be administered in the amounts necessary to decrease pain and symptoms without concern about the milligram dose required.
- Pain and symptom assessment and management, although challenging in an ICU setting, are primary roles and contributions of the ICU nurse.
- Conducting family meetings early in the ICU stay, establishing goals of care, and helping patients and families with decision-making are important aspects of quality palliative and end-of-life care.
- Decisions to forgo life-sustaining therapies are made when the burden of aggressive treatment clearly outweighs the benefits. There are two methods of withdrawing ventilator therapy: immediate extubation and terminal weaning. Guidelines exist for each of these methods of withdrawal.
- Optimal family care occurs at any point along the patient's illness trajectory by providing access, information, support, and involvement in caregiving activities.

Introduction

An intensive care unit (ICU) is, by tradition, the setting in which the most aggressive care is rendered to hospitalized patients. However, many patients die in ICUs. It is estimated that more than 500,000 people die after admission to ICUs in the United States each year.[1] In a recent retrospective cohort study, researchers reported that 35% of patients older than 80 years of age were admitted to the ICU and either died in the ICU or shortly thereafter in the hospital.[2] Investigators comparing Medicare beneficiaries' places of care and sites of death reported a significant increase in ICU usage during the last 30 days of life, with 29% of the decedents experiencing ICU care in the last month of life.[3] In addition, 36% of patients with poor-prognosis cancers who were not receiving hospice care were admitted to the ICU within 30 days of death.[4] Therefore, it is clear that management of the process of dying is common in ICUs.

In the high-technology environment of an ICU, it may be difficult for healthcare professionals and families of dying patients to acknowledge that there are limits to the effectiveness of medical care. However, it is important to focus on providing the type of care that is appropriate for the individual patient and the patient's family. This chapter discusses the provision of palliative care in ICUs, with an emphasis on end-of-life (EOL) care. Specifically, challenges and barriers to providing such care in ICUs are described, and recommendations are offered for the provision of symptom assessment and management. Current issues related to holding family meetings, establishing patient goals of care, surrogate decision-making, and withholding and withdrawing life-sustaining therapies are covered. Finally, recommendations are offered for attending to the needs of families as well as healthcare professionals who care for ICU patients at the end of life.

The Limitations of End-of-Life Care in Intensive Care Units

The ICU is rarely a place where one would choose to die.[5] Healthcare professionals in ICUs, frequently uncertain about whether a patient will live or die, are caught between the opposing goals of preserving life and preparing the patient and family for death. It is important for professionals to realize that a patient's death is not necessarily an indication of ineffective care. Yet there remain serious limitations to the care provided to seriously ill and dying patients and their families. Communication between physicians, patients, and families may be poor[6]; patients and families may be overly optimistic about the outcomes of cardiopulmonary resuscitation (CPR)[7] and have unrealistic expectations of ICU technological treatments[8]; EOL decision-making can be challenging and present conflicts[9]; and many hospitalized patients die in moderate-to-severe pain and with other troubling symptoms.[10]

Planning Palliative Care for Intensive Care Unit Patients

Providing comfort to patients should accompany all ICU care, even during aggressive attempts to prolong life. However, if a patient is not expected to survive, the focus shifts to an emphasis on palliative care. A transition period occurs during which healthcare professionals, the patient's family, and sometimes the patient recognize the appropriateness of withdrawing and/or withholding

Box 51.1 Establishing Goals of Care during ICU Family Meetings

- Ascertain whether the patient has an advance directive, a durable power of attorney, and has communicated a preference about CPR.
- Hold a patient and family meeting early in the ICU stay to identify and communicate the goals of care for the patient and discuss and update them daily.
- Outline the steps that need to be taken to accomplish the goals of care and evaluate their effectiveness.
- Use an interdisciplinary team approach whenever possible.
- In a situation where the patient lacks decision-making capacity and surrogate representation, it is recommended that a court appoint a guardian on behalf of the patient or that safeguards be put in place, such as mandatory ethics committee review, to protect the patient's interests.
- Develop and communicate the palliative care plan to professionals and family, and identify the best persons for implementing the various actions in the plan.

Source: From References 14, 15.

life-sustaining therapies (LSTs) and begin to make preparations for death. The transition period may be a matter of minutes or hours, or it may be a matter of weeks. Clearly, this time difference must be recognized as a factor that can influence the experience of a patient's family. When patients rapidly approach death, their families may not have time to adjust to the possibility of death. On the other hand, when death is prolonged, family frustration and fatigue may be part of their experience. Healthcare professionals who are sensitive to these different experiences can individualize their approaches and interventions for families.

The transition from aggressive care to death preparation has not been well operationalized. The transition period may be uncomfortable for many healthcare professionals because clinically useful prediction models recognizing which patients have the highest risk of death in the ICU remain elusive.[11] Therefore, it is important for healthcare professionals to integrate palliative care principles early in the patient's ICU stay. Researchers have found that the use of palliative care triggers and protocols resulted in prompt referrals to palliative care, lowered the use of ICU resources without changing mortality, and increased palliative care specialists for patients and families most in need.[12,13] Of equal importance is to hold patient and family meetings early in the ICU stay in order to address goals of care (see Box 51.1).[14,15]

Symptom Assessment and Management: Essential Components of Palliative Care

Pain Assessment

In spite of advances in pain assessment and management techniques, hospitalized patients continue to receive inadequate pain management.[16] Pain research focusing specifically on dying ICU patients remains scarce but advances that have been made in the assessment of pain in other critically ill patient populations can be applied to dying patients.[17,18] The patient's report of pain is still considered to be the most valid source. ICU patients, even if they are being mechanically ventilated, may be able to use simple numeric or word rating scales, word quality scales, and body outline diagrams. A 0–10 visually enlarged, horizontal numeric rating scale was found to be the most valid and feasible of five pain intensity rating scales.[17] In addition, an enlarged vertical thermometer of a self-report pain intensity scale has demonstrated validity and is preferred by older adults and critically ill patients.[19]

Many critically ill patients are unable to self-report because of their disease process, technological treatment interventions, or the effects of medications. For example, the use of high doses of benzodiazepine (BZD) infusions may make patients too sedated to respond to pain, although pain may still be present. On the other hand, the use of neuromuscular blocking agents (NMBAs) such as vecuronium may limit or entirely mask the patient's ability to express or show any behavioral signs of pain. It is essential that clinicians understand that some medications, such as propofol and NMBAs, have no analgesic properties, although visible signs of pain disappear during their use. If these agents are used, they must be accompanied by infusions of analgesics, sedatives, or both. In addition, nurses can elicit the assistance of the patient's family to help assess the patient's pain. In a study by Puntillo and colleagues, the families' ratings compared with the ICU patients' reports of pain intensity had a moderate level of agreement (intraclass correlation coefficient = 0.43).[20] In a recent qualitative study, families could describe common as well as specific behaviors indicative of pain in their loved one.[21]

When patients are too ill to communicate their pain through self-report, behavioral scales are recommended as alternative measures of pain.[22,23] According to a systematic review, the Critical-Care Pain Observation Tool (CPOT) and the Behavioral Pain Scale (BPS) have sound psychometrics[24] and are recommended by the Society of Critical Care Medicine for pain assessment of critically ill adults unable to self-report.[23] A BPS version is also available for non-intubated patients (BPS-NI) in which a vocalization item can be used instead of compliance with mechanical ventilation.[25] A new tool, the Behavior Pain Assessment Tool (BPAT), underwent validation at the international level with translation in 12 languages and testing in 3,851 ICU patients from 28 countries. Its feasibility of use in daily practice continues to be investigated.[26]

Behavioral scales are not applicable in unresponsive patients. In such a situation, no other alternative measures of pain are available. Vital signs are not valid indicators of pain,[23] but evidence has shown that they could be considered as adverse events of severe pain.[27] Exploration of other physiologic measures (e.g., pupil dilation reflex) and novel technologies is needed to provide nurses with alternative tools to use in the pain assessment process of this vulnerable population.[28] Another strategy nurses can use is their imagination to identify possible sources of pain by asking the question, "If I were this patient and had intact sensations, what might be making me uncomfortable?" Even if patients are not exhibiting behavioral or physiological signs of pain, it does not mean that they are pain-free.[23]

Procedural Pain

Critically ill patients undergo many diagnostic and treatment procedures. Many of these may be unnecessary, and some procedures such as central line placements, chest tube removal, and endotracheal suctioning, are quite painful and may be the primary cause of suffering at the end of life.[29] Nurses can act as "gatekeepers" by evaluating the appropriateness of procedures being planned for patients, especially after a decision has been made to withdraw life-sustaining treatment, and they can advocate for their omission. Practice guidelines recommend that anticipating and treating pain be part of procedural instructions.[30]

Pharmacological Management of Pain

Numerous categories of analgesics and types of modalities exist for administration to critically ill patients.[31,32] As in all situations, the selection of analgesics should depend on the specific pain mechanism, and the route and modality should be matched to their predictability of effectiveness. Although no comprehensive survey of pain management techniques used for dying ICU patients has been reported, the most common analgesic intervention is use of intravenous opioids.[31,32] Choosing the best opioid and method of delivery will depend on factors such as the patient's body composition (e.g., amount of adipose tissue), development of tolerance, and the adverse effect profiles of the various opioids.[31,32] Use of a continuous infusion of an opioid allows for titration of the drug to a level of analgesic effectiveness and for maintenance of steady plasma levels within a therapeutic range. Additionally, healthcare professionals may consider the administration of intermittent opioid boluses for breakthrough pain. Box 51.2 presents basic tenets in using opioids in critically ill patients, and Table 51.1 provides information on opioids commonly used in the ICU setting.[17,22, 31–33]

Box 51.2 Tenets of Pain Management

- Healthcare professionals should be patient advocates for effective pain control.
- Most critically ill patients will experience pain during their ICU stay.
- Healthcare professionals should assume that pain may be present especially when the patient cannot self-report or when objective measures of pain are conflicting.
- Early recognition and assessment of pain is more effective in controlling and managing pain.
- If there is any notion that the patient has pain, analgesics should be given prior to sedative agents (i.e., "analgesia first"), especially with agents that possess little or no analgesic effects.

Source: From References 22, 31.

Concerns about patients becoming tolerant of or dependent on opioids are misplaced during terminal care. What is important is that professionals recognize the development of tolerance, which is the need for larger doses of opioid analgesics to achieve the original effect,[34] and increase the dosage as necessary. There is no ceiling effect from opioids; the dose can be increased until the desired effect is reached or intolerable side effects develop. Opioid-dependent patients are at high risk of developing withdrawal symptoms,[34] which would seriously increase their discomfort. In this situation, physical dependence can be addressed by gradually lowering the opioid dose while carefully assessing for signs of pain or withdrawal.

Titration of analgesics to achieve the desired effect is one of the most challenging and important contributions that ICU nurses

Table 51.1 Pharmacology of commonly used opioids in the intensive care unit (ICU)

Agent	Equianalgesic dose (mg)		Onset	Half-life	Intermittent dose	Infusion dose range	Active Metabolites	Unique Concerns[a]
	IV	Oral						
Fentanyl	0.1	N/A	1–2 min	2–4 hr	0.35–0.5 mcg/kg IV every 0.5–1 hr	0.7–10 mcg/kg/hr	No metabolite, parent accumulates in fatty tissues	Less hypotension than morphine Accumulation in hepatic impairment Muscle rigidity
Hydromorphone	1.5	7.5	5–10 min	2–3 hr	0.2–0.6 mg IV every 1–2 hr	0.5–3 mg/hr	None	May work in patients tolerant to morphine or fentanyl Accumulation in hepatic/renal impairment
Morphine	10	30	5–10 min	3–4 hr	2–4 mg IV every 1–2 hr	2–30 mg/hr	6- and 3-glucuronide metabolite	Bradycardia/hypotension Bronchospasm Accumulation in hepatic/renal impairment
Remifentanil	N/A	N/A	1–3 min	3–10 min	N/A	1.5 mcg /kg loading dose, then 0.5–15 mcg /kg/hr	None	Bradycardia/hypotension No accumulation in hepatic/renal failure Use ideal body weight if > 30% IBW

IV, intravenous; IBW, ideal body weight; N/A, not applicable

[a] Common adverse effects associated with all opioids, such as respiratory and central nervous system depression are not listed.

Source: From References 17, 22, 31–33.

can make to the comfort care of dying patients. The desired effect can often be described as use of the least amount of medication necessary to achieve the greatest comfort along with the optimum level of tranquil awareness. In ICU settings, there may be concerns that administration of analgesics in the amounts necessary to provide comfort could "cause" death. It is essential that ICU health professionals understand the "double-effect" principle. In brief, the double-effect principle states that administration of analgesics to dying patients in the amounts necessary to decrease pain and suffering—although possibly causing unintentional hastening of death—is an ethically sound way to treat a dying patient.[35] When the ICU patient is approaching death, the most important aim of care should be to make the patient as comfortable as possible.

Nonpharmacological Management of Pain

Nonpharmacological interventions for pain management complement, but do not substitute for, the use of pharmacological interventions. Numerous therapies are available to promote patient comfort, and many of these therapies are low-cost, safe, and easy to implement. There is research evidence that ICU nurses use these therapies in their practice.[36,37] In one study, more than 92% of patients received at least one nonpharmacologic intervention while being repositioned. In this study, nurses reported that what they used the most was a calming voice and providing information.[36] In another study, ICU nurses, patients, and families described music therapy, distraction, massage, and family presence as the most relevant and feasible nonpharmacologic interventions for ICU pain management.[37]

Anxiety, Agitation, and Sedation

An important part of palliative care in the ICU is assessment and treatment of anxiety and agitation. Simple numeric rating scales for anxiety can be used if the patient can self-report. Healthcare professionals and patients are familiar with the use of the 0–10 numeric rating scales for pain. "Anxiety" word anchors can be substituted for pain word anchors so that the numeric rating scales also can be used to quantify the degree of anxiety. Unfortunately, no tool is available to assess anxiety in patients unable to self-report. However, common behavioral or physiological signs of anxiety include trembling, restlessness, sweating, tachycardia, tachypnea, difficulty sleeping, and irritability.[33]

Several agitation/sedation assessment scales are available. It is recommended to use validated scales (e.g., the Richmond Agitation Sedation Scale [RASS] and Sedation Agitation Scale [SAS]).[33,38,39] These scales can be printed on the patient flowsheet, on a separate form, or in the electronic medical record and used as a bedside assessment tool. The frequency with which the scales are used depends on the patient's condition and the schedule for evaluating treatment interventions.

Pharmacological Management to Promote Sedation in Anxious or Agitated Patients

Along with opioids, other categories of sedating drugs are frequently used in the ICU, especially for patients who are mechanically ventilated. Guidelines[22] exist regarding the use of analgesics and sedatives. Often, the goal of combined analgesic-sedative therapy is to promote physical and psychological comfort. Practice decisions include choosing the right type and combination of medications, determining whether to use interrupted sedative infusions or continuous infusions, determining appropriate clinical endpoints for pharmacological interventions,[40] and evaluating the effectiveness of sedation protocols on practices and outcomes.[41]

The appropriate pharmacological agent to control agitation and anxiety is selected according to the desired effect.[40] Benzodiazepines (BZDs) are excellent agents for anxiolysis, but they possess no analgesic or psychological properties. Concomitant use of BZDs, opioids, and certain neuroleptic agents may relieve anxiety-provoking symptoms through a synergistic action. When used together, these drugs can be administered in lower doses less frequently, have fewer side effects, and can decrease or delay development of tolerance or dependence through the use of smaller doses of each drug. At lower doses, BZDs reduce anxiety without causing central nervous system sedation or a decrease in cognitive or motor function. With increasing dosages, inhibition of motor and cognitive functions as well as central nervous system depression does occur. Sufficiently high doses can induce hypnosis and coma.[40]

The most frequently used BZDs in critical care are midazolam and lorazepam.[22] (see Table 51.2). Lorazepam gives effective sedation and anxiety relief over a longer period than midazolam. Cardiovascular and respiratory effects occur less frequently with this drug than with other BZDs. It may also act synergistically with haloperidol, a neuroleptic agent. As with opioids, tolerance to BZD effects can develop in critically ill patients. BZD dependence is evidenced by symptoms such as dysphoria, tremor, sweating, anxiety, agitation, muscle cramps, myoclonus, and seizures on abrupt medication withdrawal.[40] BZDs should also be used with caution as they may be a risk factor in the development of ICU delirium.[40]

Propofol is a highly lipophilic IV sedative/hypnotic agent that has a very rapid onset of action and short duration (see Table 51.2). It is indicated for use in the ICU to control agitation and the stress response in patients who are mechanically ventilated and those who require deep sedation for procedures.[40] However, propofol has no analgesic properties and must always be used in conjunction with analgesics whenever the patient might experience pain. During initial use of propofol, a drop in systolic blood pressure, mean arterial blood pressure, and heart rate may occur in patients with fluid deficits and in those receiving opioids.[40] The short effective half-life of propofol allows rapid clinical evaluation of the patient's level of consciousness and determination of the minimum dose required for effective sedation. This may make it a useful drug during situations in which intermittent interaction with professionals and families is desired.

Dexmedetomidine is a potent, centrally acting alpha-2-adrenergic agonist that can be used for ICU patients requiring light sedation.[42] Even though this medication does have analgesic properties, most patients will require additional opioids for pain management.[42] Continuous infusions of dexmedetomidine have been associated with bradycardia and hypotension, whereas frequent bolus doses have been associated with hypertension. Due to side effects occurring from rapid bolus dosing, it may not be the preferred choice for patients with acute agitation.[42] In addition, because this medication is metabolized by the liver, it should be used with caution in those with liver disease.[42] Current pain, agitation, and delirium guidelines suggest the use of non-BZD sedatives, such as propofol and dexmedetomidine, as the preferred choice for sedation medications.[22]

Table 51.2 Pharmacological symptom management

Symptom	Drug type most frequently used	Method of administration	Usual dose[a]
Pain	Opioids (e.g., morphine, fentanyl, hydrocodone, methadone)	Continuous IV infusions with use of intermittent boluses for procedure-related pain or during treatment withdrawal	Continuous infusion: 1–10 mg/hr morphine equivalents
			Bolus: 2–5 mg IV morphine equivalent slow push; titrate to effect
Anxiety/ Agitation	Benzodiazepines (e.g., lorazepam, midazolam)	Same as for opioids	Continuous midazolam infusion: 1–20 mg/hr
			Bolus midazolam: 2–5 mg IV
			Continuous lorazepam infusion: 1–10 mg/hr
			Bolus lorazepam: 2–6 mg IV every 4–6 hours
	Haldol	IV boluses	Bolus: 0.5–20 IV
	Propofol	Continuous IV infusion	Continuous: 50–150 mcg/kg/min
Dyspnea	Oxygen	Multiple methods (e.g., nasal cannula, mask, ventilator)	Concentration as needed
	Opioids (e.g., morphine)	Continuous IV infusion and/or IV bolus; or per nebulizer	See above for IV doses
			Per nebulizer: 2.5 mg in 3 mL saline (preservative free) or sterile water q4h
	Benzodiazepines	See above	See above
	Bronchodilators (e.g., Alupent)	Per nebulizer	Alupent: 2.5 mL 0.4–0.6% solution
	Diuretics (e.g., Lasix)	IV bolus, slow push	Bolus Lasix: 20–40 mg IV
	Anticholinergics (e.g., atropine)	Per nebulizer	Atropine: 0.025 mg/kg diluted with 3–5 mL saline three or four times daily; doses not to exceed 2.5 mg

[a] Drug doses are general recommendations. Dosing should be individualized to a particular patient. Under usual circumstances, start with low doses, wait for effect, and titrate to desired effect.

Source: From References 17, 33.

It is important that patients in ICUs be routinely assessed for the presence of delirium using validated tools such as the Intensive Care Delirium Screening Checklist (ICDSC) or the Confusion Assessment Method for ICU (CAM-ICU).[16,33,38,43] Haloperidol is a frequently used neuroleptic for critically ill patients with delirium.[33] In one study, short-term prophylactic administration of low-dose intravenous haloperidol given to elderly ICU patients after noncardiac surgery led to a significant decrease in the incidence of postoperative delirium.[44] However, there is no published evidence that haloperidol actually reduces the duration of delirium.[22] This drug does have the benefit of fewer cardiovascular effects unless given rapidly, in which case vasodilation and hypotension may occur. Haloperidol does not depress respirations; rather, it has a calming effect on agitated, disoriented patients, making them more manageable without causing excessive sedation. However, haloperidol has some significant adverse effects, such as reduction of the seizure threshold, precipitation of extrapyramidal reactions, and prolongation of the QT interval leading to torsades de pointes.[33] Clinicians may try other atypical antipsychotic medications instead of haloperidol (e.g., olanzapine, quetiapine, and ziprasidone) in treating delirium with fewer side effects.[33] Recent guidelines suggest evidence that atypical antipsychotics may reduce the duration of delirium, but they do not prevent delirium in ICU patients.[22] More robust clinical trials are needed to justify the most appropriate pharmacological treatment of delirium.[33]

Nonpharmacological Interventions for Anxiety and Agitation

Numerous interventions exist that may promote tranquillity and sedation in a critical care environment. In a recent study, Chlan and colleagues reported that patients in a self-directed music group had a reduction in sedation frequency, intensity, and medication use when compared with patients with usual care.[45] The act of physically caring for a patient and providing gentle touch is a major source of comfort for patients in critical care. Taking the time to provide simple measures such as back rubs and massages, repositioning the patient, smoothing bed linen wrinkles, removing foreign objects from the bed, providing mouth and eye care, and taping tubes to maintain patency and inhibit pulling effectively promotes comfort and decreases anxiety. For alert patients, increasing opportunities for control is a strategy that can reduce the sense of helplessness that often accompanies patients who are critically ill. Finally, facilitating communication with clergy, psychologists, or psychiatrists, if appropriate, can help to alleviate the distress experienced by both patients and families.

Dyspnea Assessment and Management

Dyspnea is a subjective experience of feeling short of breath and is one of the most distressing symptoms that can be experienced by critically ill patients at high risk for dying.[33] The gold standard for assessing dyspnea is patient self-report. A 0–10 numerical rating scale can also be used to establish the intensity of dyspnea.[46] However, most critical care patients at high risk of dying cannot self-report and give a yes or no answer.[46] In this case, the Respiratory Distress Observation Scale (RDOS) is the only known tool to assess dyspnea in these patients.[17,33,46] Management of dyspnea in patients at high risk of dying includes oxygen therapy, opioids, BZDs, bronchodilators, diuretics, and anticholinergics (see Table 51.2).[17,33]

Other Distressing Symptoms

Puntillo and colleagues[16] are one of the few investigators studying the self-reported symptom experiences of ICU patients at high risk of dying. These investigators used a 10-item symptom checklist measuring both the intensity and distress of symptoms such as pain, fatigue, shortness of breath, restlessness, anxiety, sadness, hunger, fear, thirst, and confusion. Their sample consisted of 171 patients (mean age: 58 years; 64% male); 34% were mechanically ventilated, and 19% died during their ICU stay. The most prevalent symptoms included fatigue (75%), thirst (71%), and anxiety (56%). Symptoms lower in prevalence but reported to be moderately distressful by patients included shortness of breath, pain, confusion, fear, and sadness. This study demonstrated that a significant proportion of patients at high risk of dying in ICUs experience substantial emotional and physical symptoms.

ICU nurses play a major role in alleviating distressing symptoms experienced by patients at the end of life, especially thirst. Nurses can use topical dry mouth products containing olive oil, betaine, and xylitol.[17] In addition, a recent randomized trial reported that patients using a "bundle" of thirst interventions (sprays of cold water, swabs of cold sterile water, and mouth and lip moisturizer) had significantly decreased thirst intensity and distress when compared with patients in a "usual care" group.[47] Because nurses are constantly at the bedside, they can assess the presence of the multitude of symptoms patients experience, advocate for effective pharmacological therapy, use additional nursing comfort measures, and provide for continuity of therapy. Symptom management is a special contribution that ICU nurses can make to their patients at the end of life.

End-of-life Practice Issues: Withholding and Withdrawing Life-Sustaining Therapies

Limiting LSTs in the ICU is common. It is estimated that withholding or withdrawing of LSTs occurs in 50–84% of deaths in ICUs.[48,49] Generally, LSTs are withdrawn when death is believed to be inevitable despite aggressive interventions. The American College of Physicians (ACP)[50] supports the right of a competent patient to refuse LSTs. They also note that there is no moral difference between withholding and withdrawing therapy. In addition, critical care–related professional organizations have published position papers in support of the patient's autonomy regarding withholding and withdrawal decisions.[51,52]

If patients are unable to make treatment decisions, then these decisions must be made on the patient's behalf by surrogates or by the healthcare team.[53] When surrogates are asked to participate in decision-making, it is recommended that a family-centered,[54] shared decision-making approach be used.[53] Holding interdisciplinary family meetings is an effective way for families to arrive at decisions about the patient's goals of care and may help reduce the burden and distress they experience during this time.[55] Because problems with decision-making and communication deficits around EOL care are still frequent sources of conflict in the ICU,[56,57] having a guideline to follow for conducting family meetings (see Box 51.3)[58–60] as well as using various

Box 51.3 Useful Guidelines in Conducting ICU Family Meetings

Plan and Prepare

- Review the patient history, medical problems, and treatment plan to date.
- Coordinate who on the healthcare team will attend the meeting (should be interdisciplinary and include the attending MD, bedside RN, social worker, palliative care clinician(s), and other relevant healthcare team members).
- Discuss goals of the meeting with the healthcare team, confirm understanding of the plan of care, anticipate conflicts and challenges beforehand.
- Identify one team member as meeting leader.
- Discuss which family members will be present.
- Arrange a private, quiet location with seating for all.

Open the Meeting

- Introduce all in attendance.
- Provide a succinct summary in easy-to-understand language and allow families the opportunity to correct or provide missing information.
- Establish the overall goal of the meeting and elicit family goals as well.
- Acknowledge that this is a difficult time and situation.
- Set rules for the discussion (e.g., time frame for the meeting).

Elicit Family Understanding

- Ask questions of families and listen.
- As they respond, think about questions such as, What do they understand? What do they believe will happen? What are their emotions?

Identify Preferences for Decision-Making and Information Sharing

- Identify how families prefer to receive information and the level of detail they would like to receive.
- Assess the family's preference for their role in decision-making (this can range from letting the physician decide to the family member assuming all responsibility for the decision).

(*continued*)

Box 51.3 Continued

Give Information

- Give brief information (e.g., two points you really want them to understand) and allow time for family to ask questions.
- Avoid medical jargon and try not to talk too much or focus on technical matters.
- Be transparent about uncertainty.
- If the patient is dying, be sure to use the words "death" or "dying."

Respond with Explicit Empathy to Family Emotions

- Use the VALUE, Ask-Tell-Ask, and N-U-R-S-E mnemonics (see Table 51.3).
- Don't fight but rather join family statements of hopefulness, using wish statements (e.g., "I wish I could promise that things would get better. I hope he gets better soon, too").
- See if the family can hope for the best but prepare for the worst.

After Giving Information, Ask about Concerns and Questions

- "You just got a lot of information. What questions do you have?"

Elicit Patient and Family Values and Goals

- Ask about the patient's goals, values, and previous discussion about end-of-life care.
- Frame those wishes within the context of the current medical situation.
- Avoid asking family, "What do you think we should do?" Instead, ask what they know about their loved one's preferences and maintain focus on the patient's perspective.
- Identify pertinent cultural, ethnic, or religious beliefs that may influence communication, decision-making, family relationships, and concepts of death and dying.

Deal with Decisions that Need to be Made

- Make a recommendation based on patient and family goals.
- Time-limited trials with clear endpoints may make sense in certain clinical situations.
- Do not offer treatments that are inappropriate, as when the burdens outweigh the benefits.
- Do not speak of "withdrawing care." Affirm ongoing quality of care and reassure the family that care will never be withdrawn but that the focus of care may change.

Close the Meeting

- Offer a brief summary of what was discussed.
- Offer to answer questions and assure the family that the team is accessible.
- Check in to make sure the family heard what you wanted them to hear.
- Express appreciation and respect for the family.
- Facilitate referrals to support services.

Source: From References 58–60.

communication approaches (Table 51.3)[59–61] may be helpful. In a current systematic review on family satisfaction with EOL care, investigators found that the use of palliative indicators such as quality communication, support for shared decision-making, and specific patient care measures resulted in increased family satisfaction with EOL care.[62] In another study, families reported significant improvement in satisfaction with care when they participated in interdisciplinary family meetings using a standardized approach to communication.[63]

Nurses in the ICU can be integral in family meetings and improving surrogate decision-making. One group of researchers reported that the use of a nurse as a family navigator was feasible and well received by both families and staff. This family navigator satisfied informational and emotional communication needs through daily contact using structured clinical updates, emotional and informational support modules, family meeting support, and follow-up phone calls.[64] Another group of investigators found that when nurses demonstrated concern, built rapport, demonstrated professionalism, provided factual information, and supported decision-making, families had more positive experiences. They reported that they had better coping, had hope, and had more confidence and trust in the ICU, and that it helped them make decisions and better prepared them for the impending death.[65]

When a decision to forgo LST is made in the ICU, there should be a concerted effort made to evaluate all therapies to assess whether these treatments could make a positive contribution to the patient's comfort.[38,66] Withdrawal of therapies should be preceded by chart notations of do-not-resuscitate (DNR) orders and a note documenting the rationale for comfort care and removal of life support.[49] There should be a clear plan of action and provision of information and support to the family.[67] Adequate documentation of patient assessments, withdrawal decisions and plans, therapy withdrawal orders, and patient and family responses during and after withdrawal is essential.[66]

Withdrawal of Ventilator Therapy with Consideration of Analgesic and Sedative Needs

It is important to understand the methods by which mechanical ventilation may be removed. Withdrawal of this treatment deserves the same clinical preparation as any other ICU procedure.[68] The primary goal during this process should be to ensure that patients and families are as comfortable as possible, both psychologically and physically. Two primary methods of mechanical ventilation removal exist: immediate extubation and terminal weaning (Table 51.4).[33,35,68] Debates continue as to which of these methods is optimal for the patient, and often the method is determined according to the physician's, patient's, or families' comfort levels.[69] However, in one study, Thellier and colleagues reported greater acceptance by families with immediate extubation before the death of their loved one in the ICU.[70]

Although there is considerable variability regarding the preferred approach to withdrawal,[38,54,66] recommendations regarding specific procedures for withdrawal are available.[71] Box 51.4 presents a protocol for withdrawal of mechanical ventilation for the clinician's consideration that includes specific recommendations regarding use of analgesics and sedatives.[33,35,38,66,68,71] One group of researchers found that, when using a standardized protocol for withdrawal of LSTs, 90%

Table 51.3 Helpful mnemonics for family meetings

Value Technique	NURSE	ASK-TELL-ASK
V—Value and appreciate what the family has said A—Acknowledge family emotions L—Listen to the family U—Understand the patient as a person through the family E—Elicit family's concerns and questions	N—Name "You seem distressed [or angry or worried, etc.]" U—Understand "This must be very difficult for you." R—Respect "I can see how much you are trying to honor your Dad's wishes." S—Support "We will be there to help advise you." E—Explore "Tell me more about what you are thinking/feeling."	Ask—the family to explain the situation in their own language Tell—the family the information the team needs to communicate (focus on 1–2 key points) Ask—Check for understanding, "What questions do you have?"

Source: From References 59–61.

of the patients were adequately sedated before and after withdrawal and fewer than 6% displayed symptoms such as terminal restlessness, death rattle, and stridor.[71]

It is important to provide comfort to dying patients who could experience pain and other distressing symptoms during withdrawal of mechanical ventilation. One group of investigators studying patients receiving morphine or morphine equivalents and BZDs prior to mechanical ventilation withdrawal reported that these agents did not cause unintended harm and shorten survival time.[71] In addition, patients should be withdrawn from NMBAs before withdrawal from life support.[38,66] The use of NMBAs makes it almost impossible to assess patient comfort; although the patient appears comfortable, he or she may be experiencing pain, respiratory distress, or severe anxiety. The use of NMBAs prevents the struggling and gasping that may be associated with dying but not the patient's suffering.[72] The withdrawal of these agents may take considerable time for patients who have been receiving them chronically, and patients continue to have effects from lingering active metabolites.[66]

Research to guide the practice of ventilator withdrawal and factors associated with withdrawal is limited. One group of researchers found wide variation among physicians on how and when LSTs were withdrawn. They found most used a sequential withdrawal process and preferred to withdraw forms of life support that are perceived to be scarce, expensive, invasive, or unnatural. They also found that the order of withdrawal typically included blood products, hemodialysis, vasopressors, mechanical ventilation, total parenteral nutrition, antibiotics, and intravenous fluids.[66]

Regardless of the processes used to withdraw LSTs, the critical care nurse plays a major role during the decision process and implementation of withdrawal of patients from mechanical ventilation. Specifically, the nurse can be an active member at family meetings where patient prognosis and goals of care are discussed. In addition, the nurse can ensure that a rationale for, and all elements of, the plan have been adequately discussed among the team, patient, and family. The nurse can ensure that adequate time is given to families and their support persons, such as clergy, to reach as good a resolution as possible.[67,73] The family needs reassurance that they and the patient will not be abandoned and that the patient will be kept comfortable with the use of medications and other measures.[54]

Table 51.4 Methods of mechanical ventilation withdrawal

Immediate extubation	Terminal weaning
Description	
Abrupt removal of the patient from ventilator assistance by extubation after suctioning (if necessary). Humidified air or oxygen is administered to prevent airway drying.	Physicians or other members of the ICU team (e.g., respiratory therapists, nurses) gradually withdraw ventilator assistance. This is done by decreasing the amount of inspired oxygen, decreasing the ventilator rate and mode, removal of positive end-expiratory pressure (PEEP), or a combination of these maneuvers. Usual time from ventilator to T-piece or extubation: 15–60 min.
Positive aspects	
Patient free of technology; dying process less likely to be prolonged; intentions of the method are clear.	Allows titration of drugs to control symptoms, maintains airway for suctioning if necessary, patient does not develop upper airway obstruction, longer time between ventilator withdrawal and death, moral burden on family may be less because method appears less active.
Negative aspects	
Noisy breathing, dyspnea may be distressful to patient/family.	May prolong dying, patient unable to communicate, machine between patient and family.
Time course to death	
Unpredictable. Usually shorter than with terminal weaning.	Unpredictable.

Source: From References 33, 35, 68.

Box 51.4 A Protocol for the Withdrawal of Mechanical Ventilation

I. Anticipate and prevent distress
  A. Review process in advance with patient (if awake), nurse, and family. Identify family goals during withdrawal (e.g., ability to communicate vs. sedation). Arrange a time that allows the family to be present, if they wish.
  B. Provide for special needs (e.g., clergy, bereavement counselor). Assess respiratory pattern on current level of respiratory support.
  C. Use opioids and/or benzodiazepines* to control respiratory distress (i.e., respiratory rate >24 breaths per minute, use of accessory muscles, nasal flaring, >20% increase in heart rate or blood pressure, grimacing, clutching). In patients already receiving these agents, dosing should be guided by the current dose.
  D. Discontinue therapies not directed toward patient comfort:
    1. Stop neuromuscular blockade after opioids and/or benzodiazepines have been started or increased.†
    2. Discontinue laboratory tests, radiographs, vital signs.
    3. Remove unnecessary tubes and restraints.
    4. Silence alarms and disconnect monitors.

II. Optimize existing function
  A. Administer breathing treatment, if indicated.
  B. Suction out the mouth and hypopharynx. Endotracheal suctioning before withdrawal may or may not be advisable depending on patient distress and family perception. There are no standard recommendations on the routine use of atropine (1–2.5 mg by inhalation q6h), scopolamine (0.3–0.65 mg IV q4–6h), or glycopyrrolate (1–2 mg by inhalation q2–4h) for excessive secretions. The use of these medications are individualized for each patient.
  C. Place the patient at least 30 degrees upright, if possible.

III. Withdraw assisted ventilation‡
  A. In general, the sequence should be individualized for each patient with comfort as the main goal§:
    1. Titrate down FiO_2
    2. If the patient is on assist control, change to pressure support
    3. Down-titrate pressure support 5–10 cm H_2O while maintaining RR <30
    4. Silence ventilator
    5. Deflate cuff and remove endotracheal tube (ETT)
    6. Suction excess secretions
    7. Turn off ventilator
  B. Mechanical ventilation should be withdrawn quickly with the goal to extubate to room air
  C. Constant reevaluation for distress is mandatory. A physician and nurse should be present during and immediately after extubation to assess the patient and to titrate medications. Treat distress with additional bolus doses of opioids and/or benzodiazepines as appropriate.
  D. Consider inhaled epinephrine for postextubation stridor in conscious patients.

[*] Drug doses are difficult to specify because of the enormous variability in body weight and composition, previous exposure, and tolerance. Opioid-naïve patients can be started on a bolus of 2 mg intravenous morphine titrated to effect. Patients receiving a continuous infusion of morphine can receive a bolus dose of 2 times the hourly infusion rate every 15 minutes. Patients receiving a continuous infusion of fentanyl can receive a bolus dose equal to the hourly infusion rate every 5 minutes as needed. If a patient receives 2 bolus doses in an hour of either morphine or fentanyl, it is reasonable to double the infusion rate.

[†] Usually the effects of neuromuscular blocking agents (NMBAs) can be reversed within a short period, but it may take days to weeks if patients have been receiving NMBAs chronically for management of ventilatory failure. Neuromuscular blockade masks signs of discomfort. Therefore, clinicians should feel that the patient has regained sufficient motor activity to demonstrate discomfort.

[‡] There is no one sequence applicable to all patients because the clinical situations are so variable. The pace of changes depends on patient comfort and may proceed as quickly as 5–15 minutes or, in an awake patient to be extubated, over several hours.

[§] Patients who require high levels of ventilatory support may die after small adjustments such as reduction or elimination of PEEP or decrease in FiO_2 to 21%. In such patients, the physician should be present during and immediately after the change in therapy to assess the patient.

Source: From References 33, 35, 38, 66, 68, 71.

Care for the Family of the Dying Intensive Care Unit Patient

Although the focus of care in many critical care areas is on the critically ill patient, nurses and other clinicians with family care skills realize that comprehensive patient care includes care of the patient's family. A family-centered approach to care is strongly supported by evidence-based guidelines.[54] Current research indicates that an ICU experience for families can be stressful (especially when their loved one dies in the ICU) and has been associated with symptoms of PTSD, anxiety, depression, and complicated grief.[74,75] "Family" is defined here as any significant other who participates in the care and well-being of the patient. Caring for ICU families encompasses major aspects of access, information and support, and involvement in caregiving activities.

Access

A crucial aspect of family care is ensuring that the family can be with their critically ill loved one. Historically, critical care settings have severely restricted family access and discouraged lengthy family visitation. Commonly cited rationales for this include concerns regarding space limitations, patient stability, infection, rest, and privacy; the negative effect of visitation on the family; and clinicians' performance abilities.[76,77] Some of these concerns have merit, whereas others, such as adverse patient-related issues and a negative effect on the family, have not been borne out in the literature.[78]

Many ICUs around the world routinely limit visitors to two at any one time.[79] Space limitations in critical care areas can be profound because most ICUs were designed for efficient use of life-saving machinery and staff and were not intended for EOL vigils by large, extended families. Ensuring that all interested family members have access to their loved one's bedside can present challenges to the often already narrow confines of the ICU. However, families of dying loved ones should be allowed more liberal access.[54] Patients are confronting what may be the most difficult of life passages, and they may need support from their families. Researchers assessed 153 families and 128 ICU nurses regarding their perceptions of unrestricted visiting hours in the ICU. The authors reported that families' satisfaction improved with the waiting room atmosphere, the convenience of visiting hours, and their interaction with the ICU staff. ICU nurses reported an improvement in keeping families updated about the patient's condition and also noted an improvement in families' satisfaction with care. However, nurses did report moderate interruptions to patient care.[78] Although healthcare professionals may feel that family visitation interferes with some aspects of patient care, the benefits far outweigh the risks.

Visitation of children should also be considered when a family member is dying. There is support for letting children visit the patient, become familiar with the care the patient is receiving, and allow them to understand what is going on.[54,80] Visitation has the potential to help the child cope and gives the child a chance to say goodbye. If ICU clinicians account for the child's developmental status and properly prepare the child, then children can visit a critically ill family member in the ICU without ill effects.[54,80]

Supporting family presence during invasive procedures and resuscitation is a practice supported by the Society of Critical Care Medicine.[54] Family presence during resuscitation and invasive procedures is an ethically sound practice, and ICUs should develop policies around offering this experience to families.[81] One group of researchers found that family presence during CPR significantly reduced posttraumatic stress disorder, major depression, and prolonged grief in families when compared to those who were not offered this option.[82] In addition, studies examining family presence have found that family presence may improve family satisfaction with care and improve family coping.[83]

Family presence may be stressful for healthcare professionals.[84] However, current literature reveals that family presence during resuscitation may help humanize the patient, improve communication, and help families with the grief process.[81] Currently, it has been recommended that hospitals establish formal programs that allow immediate families to be present during resuscitation. This program should include trained staff to support the family, assess the family for distress, educate the family regarding the process, and debrief after the process.[85]

Information and Support

Information has been identified as a crucial component in family coping and satisfaction in critical care settings.[62] Support, in the form of clinicians' caring behaviors and interactions, is enormously influential in shaping the critical care experience for both patients and their families.[86] In the context of caring for a critically ill, dying patient, however, nurses and physicians alike have reported high stress related to notifying families of the patient's death or terminal prognosis.[87] In general, very few healthcare professionals feel they have the skills and knowledge necessary to counsel families effectively during this emotionally charged time. However, a group of researchers designed a workshop to enhance critical care nurses' skills and confidence in discussing prognosis and goals of care with families and physicians. They found that, after the workshop, the nurses' confidence and skills in assessing families' understanding of prognosis and goals of care, addressing families' needs, and contributing to family meetings were significantly improved.[88]

Overall satisfaction with EOL care has been shown to be significantly associated with completeness of information received by families, support and care shown to the patient and family, consistency in staff, and satisfaction with the amount or level of healthcare received.[15] Interdisciplinary family conferences have been used extensively as a means to improve communication between healthcare professionals and families. Using best practices in relation to the timing, content, and participants necessary for optimal communication during a family conference have shown to lower emotional distress for families, maintain consistency with the patient's goals and values, and achieve consistent communication throughout the ICU stay.[62] Encouraging families to attend rounds has been shown to improve family satisfaction with the frequency of communication with physicians and in support with decision-making.[89] In addition, diaries may help lower distress for families. Researchers found that families who recorded a diary during their loved one's ICU stay had improved understanding of the medical information provided to them, felt a stronger connection with the patient, were able to maintain hope, and, finally, felt that diaries humanized the medical staff and the patient.[90]

Finally, because feelings of grief in surviving families are still commonly unresolved 6 months to 1 year after a loved one's death, many critical care units have organized bereavement programs.[91,92] These programs may involve providing a bereavement brochure, contacting the surviving family by telephone or mail, sending a condolence card, and holding a memorial service.[91,92] In addition to remembering and supporting the family, these programs have also been shown to help healthcare professionals cope with the loss as well.[93]

Involvement in Caregiving Activities

Few interventional studies have examined the effect of family involvement on critically ill patients and their families, yet families should have the opportunity to be helpful. One study qualitatively assessed the benefits of family caregiving. These families reported that caregiving allowed them to feel close to the patient and have confidence in the care the patient received.[94] Other researchers found similar benefits of family caregiving at the end of life. These authors reported that most families wanted to be involved in the direct care of the patient and that it would help bring them peace of mind after the death and help them feel needed and useful.[95] Acknowledging the contributions of families and involving them in caregiving activities can be beneficial. These activities can range from minor activities (such as assisting with oral care or rubbing the dying patient's feet) to major activities (assisting with post-mortem care). Nurses' facilitation of family involvement in their dying loved one's care is a practical family intervention that should be more widely employed if humane and comprehensive palliative care is desired.

Care for the Caregiver of the Dying Intensive Care Unit Patient

In a recent systematic review of compassion fatigue and burnout, numerous studies have described the tension and moral distress between the cure-oriented critical care setting and palliative care.[96] The nurse often feels caught between differing perceptions held by physicians and families concerning patient progress and treatment goals.[97] Facilitating and coordinating dialogue and consensus between these groups as well as caring for the dying patient and family can cause conflicts and can be physically and emotionally exhausting. If the dying process is prolonged, the nurse can become frustrated and fatigued. Although healthcare professionals often cope with this stress by emotionally disengaging themselves from the charged atmosphere, emotional distancing has been shown to hamper skill acquisition and the development of involvement skills and lead to burnout.[98] This section discusses two strategies to help healthcare professionals sustain their caring practices and extend their involvement skills: sharing narratives and death education.

Sharing Narratives

Debriefing has been used effectively in many settings to discuss and process critical incidents; analyze healthcare professionals' performance in terms of skill, knowledge, and efficiency; and learn, both personally and institutionally, from mistakes and system breakdown.[99] Sharing stories or narratives of practice can be used to achieve the same goals, but telling stories from practice also enables clinicians to (1) increase their skill in recognizing patient and family concerns; (2) learn to communicate more effectively with patients, families, and other healthcare professionals; (3) reflect on ethical comportment and engaged clinical reasoning; and (4) articulate clinical knowledge development.[100]

Death Education

Closely coupled with sharing clinical narratives is the use of seminars and other reflective exercises aimed at preparing nurses and other healthcare professionals for the care of dying patients and their families. Death education often consists of didactic and experiential classes. Participants in these classes are encouraged to reflect on and share their own perceptions and anxieties about death, as well as their attitudes toward care of the dying patient and his or her family. This approach has been used with varying degrees of success with nurses and physicians.[101,102] Because many healthcare professionals feel ill-prepared to effectively care for terminally ill patients and have also identified barriers to delivering quality EOL care, this strategy deserves more implementation and research.[103] Box 51.5 discusses key educational components in integrating palliative care into the ICU.[62,63,88,101,104]

Box 51.5 Key Educational Components to Incorporating Palliative Care into the ICU

- Educate critical care staff about palliative care (e.g., principles of shared decision-making, communication techniques, symptom management, and practices of withdrawal of life support) through lectures, workshops, pamphlets, teaching videos, simulation, role play, and poster boards.
- Train local ICU champions who can serve as role models and facilitate behavior change through half-day or full-day training sessions.
- Collect feedback on quality improvement data (e.g., families' satisfaction with care or families' ratings of the quality of death and dying).
- Utilize system supports and hospital resources to develop family informational pamphlets (e.g., "get to know me" posters for patients' rooms and developing withdrawal of life support forms).

Source: From References 62, 63, 88, 101, 104.

Case Study: A Patient in the ICU

From: "I Was Afraid That There Was a Window and It Was Closing": Primary Palliative Care as Bridge to Transplant.

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With acknowledgment and gratitude to the patient and family whose story follows, and who not only gave permission for it to be told but took time after leaving the hospital to tell it to me in their own words.

Seth Palmer was looking forward to going back to college in the fall, but was concerned about the fatigue, shortness of breath, and loss of appetite that only seemed to be getting worse. One night, Seth dropped down the rabbit hole of critical care as a spontaneous pneumothorax sent him to his local emergency department (ED), then on a 3-month journey from ICU to ICU. A lung biopsy indicated fibrotic nonspecific interstitial pneumonia. As it was unknown whether Seth's lungs would recover even with maximal medical therapy, he was moved to a regional transplant center for further management and workup.

When Seth arrived from the referring hospital, he reported insomnia, weight loss, severe pain, anxiety, and dyspnea. Palliative care became a central theme of his 3-month journey through critical illness. Seth and his family, particularly his mother Carol, were active partners. The Palliative Care Consult Service provided expert guidance on managing his challenging symptoms in ways that minimized impact to his fragile respiratory status.

On his first day in the ICU, Seth overheard a physician rounding outside the room saying "We're probably going to need to look at a trach." The following day, a person came in with a clipboard to get consent. Carol walked the physician out into the hall. "At this point, you're building trust and this is what is happening?" The trach went ahead, and more attention was paid to involving Seth directly in conversations and decisions regarding his treatment. Care conferences were held at the bedside. "They listened. They knew you brought something to the table. They gave credit for our contribution to the team." Clinicians prioritized work with speech and respiratory therapists in using a Passy-Muir valve on Seth's trach so that he could speak. For months, Seth most often communicated by writing on a white board, so these opportunities to have a literal voice were especially precious.

Traditionally, sedation and delirium have hindered ICU patients' attempts to communicate their symptoms, questions, and goals of care. Multiple disciplines collaborated on Seth's behalf to develop medication and ventilator support regimens to maximize his awake time during the day while promoting sleep at night. This proved to be tremendously challenging from the start and only became more so as time went on. He initially received dexmedetomidine infusion for sedation and fentanyl infusion with PRN boluses for analgesia. Dexmedetomidine was weaned off with assistance from an enteral clonidine taper. Fentanyl was transitioned to oxycodone. These changes seemed to exacerbate insomnia, so mirtazapine and melatonin were added at bedtime. Seth's worst pain was centered on the chest tube insertion site, so lidocaine patches were placed at that area.

Seth identified time with family and friends and opportunities to be creative as coping strategies that had worked for him in the past. The ICU volunteer team brought art supplies and visited him on days when fewer family members could make the 3-hour round trip to the hospital. Music therapy, animal-assisted therapy, and Spiritual Care Services were crucial in alleviating anxiety, promoting resilience, and transforming Seth's quality of life in the ICU. As Seth said later, "The music thing was HUGE. I was able to smile and the first time I felt like singing was when they brought in the guitarist." He looked forward to visits from Duke, Hank, and Smidge—the ICU's therapy cat and dogs.

Having clinicians come into his room rather than observing from the hall meant a lot. They were "looking out for the patients, looking in and acknowledging them when walking by." This was especially important at night, which Seth noted was a particularly scary time in the ICU. Other times, though, "it felt like I was in a viewing box and they were examining me as a patient not as a person—it was dehumanizing." Seth's ICU had a Continuity of Care (COC) program, in which nurses could sign up to be preferentially assigned to a particular patient with whom they had established rapport. Having these nurses for Seth improved all three domains of primary palliative care: symptom management, communication, and family support. These nurses carried the longitudinal memory of effective pharmacologic and nonpharmacologic measures and could identify opportunities for early intervention. As Seth reported later, "The continuity of care list—that was huge. . . . I was proactive in trying to get those nurses. I advocated for myself to get my COCs." For someone spending 3 months on a ventilator in the ICU, the value of having an opportunity to advocate for yourself is hard to overstate.

Seth described his focus during those early weeks as "getting better on my own. I was not considering a transplant, didn't even want to think about it." He had become very deconditioned already due to the steroids required for his pulmonary disease as well as profound dyspnea with exertion and difficulty maintaining adequate nutrition. "A lot of times I did NOT want to do it. I was so weak . . . it was really difficult . . . couldn't get out of bed. [The physical therapist] made a huge difference trying to get up." Seth's respiratory therapists worked with him on identifying which transport ventilator was easiest to breathe with during activity, as well as which modes and settings were most comfortable. During ambulation, staff would follow behind with a wheelchair so that he could pause to catch his breath mid-walk and then continue rather than cutting the session short. "Over time I could push myself further. To get physical again . . . to reclaim my body. To be able to go further, faster, seeing my body come back again was big." Physical and occupational therapists tried to stagger visits to permit rest in between sessions.

The Palmers continued to meet with the team. Their goal became "get better, go home and maybe down the line . . . a transplant." Oxygen and suctioning needs increased over the next 6 weeks. Additional chest tubes were placed as Seth's lungs repeatedly collapsed and were more resistant to re-expanding. The transplant team was checking in daily. While Seth was willing to consider transplant as a hypothetical distant possibility, that was as far as he could go. "I was the last one to get on board with that. Everyone was pushing me in their own ways." Carol was solidly in Seth's corner advocating for him no matter who came in the room. "I was pushing my agenda . . . I was afraid that there was a window and it was closing."

Seth's weight had dropped to 44 kg, too low for transplant even if he consented to have one. As Seth told one of his nurses, "I need to eat more but the thought of food grosses me out." Nausea made it difficult to keep food down. Promethazine and prochlorperazine were added with positive results. Family members were encouraged to eat with Seth and help him maintain as close to a regular diet as possible. Calorie count logs showed that food by mouth was not meeting his energy and protein requirements. A feeding tube was placed and enteral nutrition started. Oxandrolone was added and Seth's weight increased to 50.9 kg, bringing his BMI into the transplantable range.

As Seth's respiratory function worsened, his quality of life did as well. All teams and disciplines involved in his care looked to what could be done differently to improve each day. Around-the-clock acetaminophen and tramadol were added to the pain regimen. Oxycodone was initially weaned due to concern for respiratory depression but then restarted for pain refractory to all other interventions. This was eventually augmented with rescue fentanyl. Mirtazapine was increased and trazodone added at bedtime to promote sleep. During the daytime, Seth reported, "I felt really claustrophobic and anxious. The therapy dog really helped." Seth downloaded a mindfulness app onto his phone and worked with it each day. The Palliative Care Service chaplain and social worker led guided meditations. Seth continued to receive frequent visits from the hospital chaplain and Roman Catholic priest for prayer and sacraments.

Seth identified breathlessness as a key instigator of anxiety during this time. He had developed a chronic cough, which exacerbated his shortness of breath and placed him at increased risk for additional pneumothoraces. Gabapentin was added as an antitussive. The various teams involved in managing Seth's ventilator support worked with respiratory therapists, nurses, and Seth himself on setting a schedule of brief trach collar episodes with bracketing periods of bilevel positive pressure ventilation. Seth described the use of positive pressure ventilation, particularly at night, as being more comfortable than the trach collar. The speech therapist returned to work with him on using the Passey-Muir valve in line with the ventilator, so that he could still enjoy periods of speaking.

Physical therapy sessions became 5 days per week, twice per day. On the best days, this would involve ambulating in the hall with a walker, initially 25 feet but over time working up to 150 feet. Other sessions focused on core and upper body strength by sitting at the edge of the bed and using resistance bands. Diarrhea briefly made participating in physical therapy difficult, but resolved with changing to a non-soy-based enteral formula and starting loperamide.

Seth and Carol endorsed the impact of the ICU environment on his symptoms. Low lighting and therapeutic music were helpful, whereas the bright lights and frequent alarm sounds were stressful. “One of the biggest things to comfort me was adding that human factor in. My mom kept bringing things in . . . to make my room my own as much as it could be.” A favorite object was a Himalayan salt rock lamp, which cast a warm glow at night. Seth found a creative outlet working with Legos and his room became populated with a multitude of figures.

Staff had a profound influence on Seth and his family. “The biggest difference between a good nurse and a bad nurse to me is empathy. Treating me like a human being, like someone they knew—with respect, with love. They made conversation, made me laugh. They didn’t treat me like a specimen.” What this said to Seth was that he was still himself. Underneath the tubes and wires and problem lists and closing windows, he was a human being with a life. The trust that this team had missed on that first day had built over weeks of relieving suffering, supporting Seth and his family, and cultivating open communication. Eventually, “I told them—‘put me on the list’ and it all happened within a week.” It was a whirlwind final week, with Seth being emergently transferred from the medical to the cardiac ICU to be placed on extracorporeal membrane oxygenation (ECMO) and finally taken to the OR for his transplant. Throughout the big night, his family waited back in the medical ICU with the nurses who had hoped and prayed right alongside them for 3 months.

We are grateful to our colleagues on the Palliative Care team for everything they taught us that helped bring Seth successfully to transplant, and to our cardiac ICU and stepdown unit colleagues for their part in the rest of his story. Seth told many of his ICU caregivers that what matters is to be a source of support and inspiration to others. Hopefully in his story, as told here, there is something to bring back to your own practice to help the next Seth rise to whatever challenge he or she is facing.

Conclusion

Striving to relieve suffering from pain and other distressing symptoms and providing a dignified death is the right of all ICU patients. Research has offered some guidance for managing the issues that surround ICU patient deaths. However, Peden-McAlpine and colleagues[105] present important goals to consider during an ICU patient’s dying process: (1) honor the patient’s life, (2) ensure that the patient and the family are not abandoned, (3) provide a sense of moral stability, (4) ensure the patient’s safety and comfort, and (5) facilitate saying goodbye. Intensive care unit nurses can feel privileged to strive toward the accomplishment of those goals.

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CHAPTER 52

Palliative Care Nursing in the Outpatient Setting

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Key Points

- The ambulatory setting is an important site for the provision of palliative care as the majority of care for chronic life-limiting illnesses is provided in outpatient clinics.
- Nurses and advance practice registered nurses play a key role in the provision of palliative care in the outpatient setting.
- Studies show early involvement of outpatient palliative care in the setting of advanced illness can promote better quality of life, reduce emergency department visits and hospitalizations, promote earlier hospice enrollment, and may prolong life.
- Palliative care in the ambulatory setting is expanding from its initial focus on oncology to other disease settings such as cardiology, pulmonology, nephrology, neuromuscular diseases, and gerontology.
- *Primary palliative care* refers to the first-line management that should be a part of the management of any chronic disease. All nurses in the outpatient setting should be able to provide fundamental pain and symptom management and coaching in basic advance care planning.
- Involvement by palliative care specialists is appropriate for patients with complex pain and symptom problems, high levels of psychosocial distress, or unusual disease characteristics.

Introduction

The vast majority of healthcare in the United States is provided in ambulatory care clinics. Patients are living longer and with greater disabilities than ever before.[1] In addition to advanced cancer, other terminal diseases that are managed in ambulatory care include end-stage heart failure, chronic lung diseases, advanced cirrhosis, kidney failure, and terminal neurological disorders such as advanced dementia and amyotrophic lateral sclerosis (ALS).

Primary and specialty care providers are central in the care of these advanced illnesses, but they receive minimal training on end-of-life (EOL) care and are challenged to find the time to address these essential issues.[2,3] Nurses and advance practice registered nurses (APRN), with their extensive psychosocial training, and in conjunction with an interdisciplinary team, play an important role in helping ambulatory clinic patients and caregivers navigate concerns that arise as the disease progresses.[4] This chapter addresses the provision of palliative care in the adult outpatient setting, with a focus on the role of nurses and APRNs.

Key Studies in Outpatient Palliative Care

Although experts agree that the well-defined benefits of inpatient palliative care in terms of improving clinical care, quality of life (QOL), and healthcare utilization probably extend to the outpatient setting, research in this area is still in the early stages.[4,5] Rabow and colleagues summarized some of the seminal studies in outpatient palliative care.[5] The key findings of the studies were improved symptoms, improved patient and family satisfaction, increased survival in those with lung cancer, and decreased healthcare utilization.[5] Discussed here are some important studies in outpatient palliative care which utilized APRNs.

The landmark study by Temel et al. examined the effect of providing early palliative care to patients recently diagnosed with metastatic non–small cell lung cancer (NSCLC; which typically has a prognosis of less than a year) in a non-blinded randomized controlled study.[6] An APRN was part of the palliative care team.[7] The patients in the palliative care arm lived 30% longer than the control group (11.6 vs. 8.9 months) and reported better QOL with fewer symptoms of depression despite receiving less aggressive treatment. Patients in the palliative care group also enrolled in hospice earlier, thus benefitting from that service for a longer period of time.[6]

In a pilot study led by an APRN, Prince-Paul et al. examined the impact of palliative care in adults with advanced cancer in an outpatient oncology clinic. Those in the palliative care arm were 84% less likely to be hospitalized and 25 times more likely to be alive at 4 months compared to the usual care group.[8]

Murphy et al. analyzed the impact of an APRN-led service providing both primary care and palliative care in the outpatient setting at a large county hospital. They found a 27% reduction in use of emergency services and a 20% reduction in hospital admissions. Patients with dementia, heart failure, chronic obstructive pulmonary disease (COPD), and those who lived in adult family homes or skilled nursing facilities had the most significant reductions with this model. However, patients with end-stage renal disease (ESRD) and chronic noncancer pain had minimal changes in these two endpoints.[9]

Primary, Secondary, and Tertiary Palliative Care

Primary palliative care describes the role of each nurse, APRN, physician, and other healthcare provider in recognizing and addressing palliative care needs.[10] The ability to provide core palliative care competencies such as symptom management, advance care planning (ACP), and communication are essential skills in all primary care and specialty care settings because there will never be a sufficient number of specialty palliative care providers to meet all needs.[2,11] In this chapter, the term *primary clinician* is used to refer to the provider who directs the care related to the life-limiting illness. The primary clinician may be a primary care provider, oncologist, cardiologist, pulmonologist, neurologist, nephrologist, surgeon, or other provider.

As palliative care continues to evolve, the majority of services will be delivered in ambulatory settings over a longitudinal basis.[12] Thus, when a patient arrives in a pulmonary clinic for a posthospitalization visit after a COPD exacerbation, the nurse may inquire whether any discussions occurred regarding ACP and code status during the recent inpatient stay. Information on advance directives (AD) must be provided to patients at the time of admission, but the paperwork may not be completed. The pulmonary clinic nurse can assist with finalizing the AD forms during the clinic visit or request a social worker to meet with the patient and family. Another example of “primary palliative care” in symptom management is the oncology nurse who assesses the patient’s response to a bowel regimen for opioid-induced constipation and makes further recommendations based on an agreed upon treatment algorithm. Ambulatory care nurses and social workers also play a key role in providing education and support in the decision to transition to hospice care. In other words, every clinician fulfills a role in “primary palliative care” on an ongoing basis.

Secondary palliative care, also known as *specialist palliative care*, refers to the formal involvement of palliative care experts to assist with more complex cases.[13,14] Problems addressed may relate to complicated pain or symptom management, maladaptive coping and distress, or assistance with particularly challenging EOL situations. As outpatient palliative care expands into nononcology fields, such as cardiology or neurology, palliative care specialists must become familiar with the specific topics that arise in various fields. Some topics are common to all fields, such as ACP and discussing patient goals and preferences for care. Other topics are unique to a specialty, such as decisions regarding cessation of dialysis in the patient with ESRD, organ transplant decisions, or initiation of advanced heart therapies such as left ventricular assist devices (LVAD) as a destination therapy.[11]

Tertiary palliative care describes major palliative care programs usually located in academic medical centers with a focus on research and teaching to advance the specialty and may include a palliative care fellowship program.[10]

Models of Care

Three basic models exist in the delivery of outpatient palliative care: collaborative, consultative, and medical home.[10] The *collaborative* model (also known as embedded, integrated, or concurrent model) is the most popular style found in the outpatient setting and has been utilized extensively in the oncology setting.[3,14] In this model, the palliative care team takes the lead in managing certain aspects of care, such as writing prescriptions for management of pain and symptoms, counseling for existential distress, and facilitating goals of care discussions, thus allowing the primary clinician to focus on the overall management of the patient’s disease condition. An advantage of this model is that it combines “the best of both worlds,” with specialists from both fields contributing to personalized care and working together to improve QOL in distinct, yet complementary roles.[15] Embedded clinics, discussed later, create the opportunity for a shared visit with the clinician, thus improving communication and coordination of care. This model is usually more convenient for the patient, especially if palliative care visits are on the same day and location as another clinic appointment. However, it creates special challenges for the scheduling of palliative care visits for this coordination.[16] The palliative care team must foster a good relationship with the referring clinician and be flexible and willing to work within the framework of the individual clinician’s style of practice.[10]

In the *consultative* model, the palliative care provider evaluates patients and forwards management recommendations to the team for implementation. The palliative care team does not actually implement the recommended plan of care (such as initiation of an antidepressant and a referral to psychology), nor does it typically follow patients on an ongoing basis. Consequently, this model suffers from a lack of follow-through on the palliative care recommendations. Rabow found a low percentage of patients had their plan of care implemented when utilizing a consultative model in a primary care clinic to address pain and depression, among other issues.[5] Nonetheless, patients showed improved scores on multiple measures, indicating that the consultative visit had an impact even if the recommendations were not instituted by the primary clinician.

The final model of care in outpatient palliative care is the *medical home model* (defined in the literature as the “primary palliative care” model, but this is different from the same term discussed earlier). In addition to managing typical palliative care issues, in this model, the palliative care team functions as the “medical home” or “primary care provider” and addresses *all* aspects of the patient’s care, from management of the life-limiting illness (such as liver failure) to other chronic conditions such as hypertension and osteoarthritis.[3] This model is excellent for medically underserved populations, high utilizers of medical services, and those in adult family homes.[9] The clinician must have a broad knowledge base and access to specialists for formal or informal consultation. In many ways, this model is comparable to services traditionally provided by general practitioners for decades.[3,13]

Benefits and Challenges Faced in the Outpatient Setting

The ambulatory setting is ideal for providing palliative care, as the pace is less crisis-driven than inpatient care, and patients can benefit from long-term trusting relationships that form with the medical team over months and years. These factors permit dialogues regarding ACP and the patient’s goals of care to be held over a series of visits. The clinic setting provides the opportunities for patients and families to work together with the palliative care team to develop plans for future care.

Presence of an outpatient palliative care team can assist with seamless transitions between inpatient and outpatient care to address ongoing supportive care needs in both settings.[13] Early involvement of palliative care in the outpatient setting may improve

QOL, reduce emergency department visits and hospitalizations, reduce healthcare costs, and reduce inappropriately aggressive care in late-stage illness, while promoting transition to hospice enrollment in a more timely manner.[5,6,9] Although more research is needed, the results of several studies suggest that early involvement of outpatient palliative care may have a survival benefit when compared to usual care in the oncology setting.[6,8]

Many challenges faced in the outpatient setting are common to palliative care teams in any setting, such as receiving late referrals (when a patient is actively dying) and funding issues.[3,5] Determination of prognosis is a challenge with any life-limiting illness, but is particularly difficult for those with heart failure, COPD, renal failure, and dementia, making the timing of hospice referral uncertain.[17–19] Other issues are specific to the outpatient setting, such as coordinating outpatient palliative care visits with the primary team's appointments. Providing seamless coordination of care with the primary clinician takes time, which may present a challenge for teams with limited personnel. Likewise, the ability to provide a 24-hour on-call presence is usually limited to larger services.

A unique issue faced by some outpatient palliative care programs is referrals for management of chronic pain not related to the primary diagnosis (e.g., chronic low back pain requiring opioid therapy in a patient with a curable leukemia) or ongoing management of chronic pain in a cancer survivor years after completion of therapy.[3] Because most outpatient palliative care programs focus on patients with life-limiting illness, the long-term management of complex chronic pain problems may be beyond the parameters of what a palliative care team can offer and may decrease the availability of practitioners to see new consults.

Practical Details in Providing Palliative Care in the Outpatient Setting

Many questions arise when developing or expanding an outpatient palliative care program. This section will address common issues in implementation of palliative care.

Team Members

The outpatient palliative care team may range from a single part-time nurse to a fully staffed interdisciplinary team working in a wide range of outpatient settings and with clinic appointments available daily. In a survey of 20 outpatient palliative care programs in a variety of practice settings, 19 clinics utilized physicians, 10 sites had APRNs, 14 had registered nurses, and 12 had social workers.[3] Other palliative care team members may include chaplaincy, pharmacy, nutrition, and rehabilitation medicine staff such as physical, occupational, or speech therapists.[20] Inclusion of a social worker in the outpatient palliative care team may increase the rate of AD completion, in addition to providing psychosocial support.[21]

Palliative Care Referrals

Leaders in oncology, cardiology, and pulmonology recommend palliative care involvement for those with serious illness.[22–24] Although such widely inclusive referral criteria are ideal, they are probably not realistic due to limitations in palliative care resources. The National Comprehensive Cancer Network (NCCN) guidelines on palliative care list a broad range of referral criteria, but a strategy is needed to identify those most in need of a referral to secondary- or tertiary-level palliative care specialists.[25,26] Glare and colleagues developed a screening tool for palliative care referral in an outpatient gastrointestinal oncology clinic based on the NCCN palliative care guidelines. By the broadest criteria, *all* patients seen in that clinic met the threshold for a referral to palliative care.[27] Instead, the authors suggest screening for distinctive palliative care needs at the initial visit, posthospitalization, and every 6 months thereafter. In a quality improvement project at a National Cancer Institute (NCI) cancer center, the Edmonton Symptom Assessment Scale was utilized in the oncology clinics to measure symptom burden as a trigger to palliative care referral. The implementation increased referrals from 1 per month to 10 per month with the use of this tool. However, the authors noted that the referral rate remained low despite the reportedly high symptom burden in many patients.[28]

Referrals to outpatient palliative care also depend on multiple factors unique to the individual provider, clinic milieu, and organizational setting. In a profile of four outpatient palliative care programs, Smith reported the following referral sources: inpatient palliative care service (10–50%), oncologist (20–60%), and primary care provider (20–30%).[3] Other referral factors include the needs and expertise of the referring clinician's access to supportive care services in the referring clinic (such as a social worker), percentage of patients in the practice with complex needs, and availability of palliative care clinicians. Close physical proximity to the referring clinician appears to play a major role in generating consults.[10,16] However, each referring clinician has different evaluation criteria for who would benefit most from employing the palliative care team.[29] Triggers for referral may be based on diagnosis, symptoms, or psychosocial factors.[26]

The results of a qualitative survey at three academic cancer centers identified oncologist barriers to referrals. The three reported barriers were the mistaken belief that palliative care was not compatible with cancer therapy, the belief that palliative care should be provided by the oncologist, and knowledge deficits of local resources.[30] Thus, palliative care referral patterns may be influenced by many factors, and there is a continuing need for education and work to improve collaboration and appropriate referrals. Box 52.1 lists common criteria for a consult to outpatient palliative care.

Establishing an ongoing referral base is important when building and maintaining a palliative care outpatient practice. The embedded palliative care practice model creates the most referrals, especially if the team can see a new consult soon after, or even concurrently with, the referring clinician to assist with "bad news" discussions, complex treatment decisions, or complicated symptom management.[10]

Embedding palliative care in a clinic associated with high symptom burden and psychosocial distress allows for palliative care concerns to be addressed promptly.[10] Examples of such models exist at several major medical centers with multidisciplinary clinics treating pancreas cancer, breast cancer, or heart failure. Patients who would benefit from palliative care intervention, such as those with metastatic malignancies, uncontrolled pain or symptoms, or significant psychosocial distress are identified during the case discussions with the entire team. The palliative care provider meets the patient that same day, as part of the multidisciplinary clinic's "package" of visits, with follow-up visits as needed. This embedded model is favorably viewed by patients, caregivers, oncologists, cardiologists, and medical center administration while increasing palliative care visibility

Box 52.1 Some Suggested Referral Criteria to Outpatient Palliative Care

Patient/Symptom Characteristics

- Poorly controlled pain, or other symptoms
- Limited treatment options, or declining functional level, accompanied by significant distress
- Frequent hospitalizations
- Diagnosis of highly fatal malignancies, such as metastatic non–small cell lung cancer, glioblastoma multiforme, metastatic pancreas cancer, or esophageal cancer
- Malignancies associated with high symptom burden, such as pancreas cancer
- Brain or leptomeningeal metastasis, spinal cord compression
- Anticipated poor outcomes, such as elderly patients with acute myelogenous leukemia, or pretransplant for a "high-risk" stem cell transplant
- Enrollment in a Phase I or Phase II chemotherapy trial
- Patient election for advanced heart therapies or preoperative for left ventricular assist device (LVAD)
- Decisions regarding feeding tubes or tracheotomy for neuromuscular diseases such as amyotrophic lateral sclerosis (ALS)
- Patient election to forego or discontinue renal dialysis
- Complex symptom management or decision-making in end-stage cardiac, pulmonary, renal, hepatic, or neurological diseases

Psychosocial Circumstances

- High levels of psychological, social, or spiritual/existential distress
- Poor social support
- Inability to engage in advance care planning discussions
- Family discord in decision-making
- Requests for hastened death

Source: From References 3, 13, 18, 20, 22, 26, 45, 69, 71, 98.

and generating ongoing referrals.[5] Use of palliative care rounds, such as the Schwartz Rounds, in which complex patient cases are discussed, are other sources to generate referrals.[31]

In most settings, a formal medical provider referral is required as a billing requirement for an initial consultation. However, in one NCCN oncology center, any clinician—including nurses, social workers, physical therapist, and chaplains—can refer to outpatient palliative care, and many referrals are initiated by nursing. Nurses form close relationships with patients over months and years of cancer therapy and frequently have in-depth discussions about coping with disease and uncertainty. If the patient experiences worsening symptoms or distress that is not well managed at the primary palliative care level (e.g., nurse or oncologist level), the team nurse may request palliative care involvement for expert assistance. Additionally, patients are allowed to self-refer to palliative care in that setting.

Timing of Outpatient Palliative Care Referrals

The literature supports early referral to outpatient palliative care to have the best effect.[6,24] In a comparison of early versus late referrals, early palliative care predominantly provided in the outpatient setting resulted in improved quality outcomes, less intense medical care, and lower cost; whereas late palliative care referrals were mostly delivered in the hospital setting and were associated with higher medical costs.[32] Unfortunately, many referrals to outpatient palliative care are late in the disease trajectory, when hospice referral is more appropriate.[26] This makes outpatient palliative care consultation less effective, although there are concerted efforts to move outpatient palliative care referrals "upstream" for greater benefit.[5]

New Patient Referrals

When receiving a palliative care referral in the outpatient setting, it is important to ascertain several key points.[16]

- First, *what is the purpose of the consult?* If the referral only indicates, "palliative care, evaluate and treat," it is helpful to speak with the referring team to ask what specifically triggered the request for this patient. Are there signs of maladaptive coping with progressive disease? Is the caregiver insisting on aggressive treatment when the patient desires to stop therapy? Is the patient experiencing ongoing severe symptoms despite standard treatment? A few minutes spent clarifying the consult can help the palliative care team determine the appropriateness of the consult and better understand the situation.
- Second, *what is the urgency of the consult?* Should the consult be scheduled immediately, or can the initial palliative care visit be held when they return for the next outpatient clinic visit in a few weeks? An important observation is that what is deemed urgent by the referring source may not appear urgent to the palliative care team, or even to the patient.[10] For example, the patient may express high levels of distress to the team, asking for help as soon possible, but then decline to schedule a next-day appointment with the outpatient palliative care team.
- Third, *is the patient and caregiver aware of the consult?* Even if they are aware, it is surprising how many perceive the palliative care referral as abandonment and ask the scheduler: "Is this how Dr. Jones is telling me he's given up on me?" Therefore, the scheduler has an important task when setting up the initial visit, which is to explain the purpose of palliative care involvement. If there appears to be any confusion or hesitation, the referring team should be notified and asked to assist with communication regarding the referral.

The wait-time from referral to first outpatient palliative care appointment is ideally less than 2 weeks, with urgent consults seen earlier if possible.[3] This may be a challenge for many programs due to provider staffing limitations. If the palliative care physician or APRN schedule is filled and an urgent consult cannot be accommodated, a palliative care nurse, if available, may assist by assessing the patient's needs in person or by phone and make recommendations to the primary provider until the patient can be scheduled with the outpatient palliative care provider.

Maintaining a Good Relationship with the Referring Provider

Success in providing outpatient palliative care in the collaborative model requires maintenance of positive relationships with the referring clinician, the team nurse, and other team members.[16,29] It may be helpful to think of the referring provider as the "customer" and palliative care as the service they are "buying." Close communication and a respectful approach are key, along with negotiation of "who does what" in patient care.[16] For example, opioids for pain management and cough are prescribed by the palliative care service, but the oncologist prescribes 3 days of steroids to reduce chemotherapy-induced nausea with each cycle. It is important for the supportive care team to respect the provider's specialized skills, acknowledging that he or she has known the particular patient for years, even decades. In addition, it is helpful to recognize that the referring clinician, as the "captain of the ship," may feel a bit threatened when referrals to palliative care are generated by another source, especially if he or she perceives that symptoms and distress are well managed.[16] Direct voice-to-voice communication with the primary team should be a priority if major issues arise, such as the patient requests to discontinue disease-directed therapy and enroll in hospice. Although this coordination of care can take a significant amount of time, such coordination may help maintain positive relationships, avoid misunderstandings, assure future referrals, and optimize patient-centered care.

Because there are many drug interactions with disease-directed therapies, especially in oncology care with the emergence of immunotherapy, it is incumbent upon the supportive care team to consult with the team pharmacist or pharmaceutical references before writing new prescriptions. This will prevent serious drug interactions (e.g., methadone, ondansetron, and citalopram all cause QT prolongation) and will highlight the contraindication of use of certain medications with certain therapies (such as avoiding acetaminophen in the immediate posttransplant setting because it will mask a fever). In centers with ongoing clinical trials, it is essential to check with the research team to ensure that any new medications (such as antiemetics) are not contraindicated by the study protocol.

Components of the Palliative Care Visit

Patients dealing with serious illness have many needs impacting multiple domains of suffering. Determining which issues to address at the initial outpatient palliative care visit depends on the needs identified by the patient and the stated purpose of the consult (e.g., symptom management, assistance with goals of care), as well as by the specialty of the supportive care clinician (chaplain vs. a pain specialist).

Three key domains are the focus of most outpatient palliative care visits: (1) pain and symptom management, (2) addressing psychosocial and spiritual needs, and (3) discussing future care decisions.[6] At the initial visit, the palliative care provider introduces the palliative care team's role, shares the referring provider's consult request, and asks the patient what are the most important issues he or she would like addressed during the visit. Thus, the palliative care provider addresses the patient's priorities as well as the referring provider's, with additional issues deferred to follow-up visits.

Length of Palliative Care Visits

The literature indicates a variety of visit lengths for outpatient palliative care, but a key consensus is that providing palliative care takes time, and quality care cannot be rushed.[5] Initial visits generally range from 60 to 90 minutes and follow-up visits from 30 to 60 minutes.[3] However, many clinicians discover that returning patients often need as much time as patients at the initial visits.[16] This is because disease progression leads to an increase in the number and intensity of symptoms, news of progressive illness creates worsening distress, and EOL decision-making becomes more of a priority. In addition to the patient visits, a significant amount of palliative care time is spent in coordinating care with the specialty clinician, which may take 5–15 minutes before and after each visit.[20] Such coordination helps to synchronize treatment approach, delineate roles, and maintain a strong relationship with the primary clinician.

Clinical Measures Utilized in Outpatient Palliative Care Visits

A variety of instruments are utilized to gather research data during palliative care clinic visits.[6,33] These fall into the major categories of functional scales, global symptom scales, pain scales, psychological and social measures, spiritual assessment, and QOL scales.[20] However, it is not clear which measures are optimal for use in everyday clinical (nonresearch) practice. Use of an assessment measure is optimal; one study found a 10-fold increase in reported symptoms with a formal tool as compared to open-ended questioning by a provider.[34]

The following scales are commonly used in ambulatory palliative care clinical practice:

- Edmonton Symptom Assessment Scale[35] (ESAS; a global scale of distressing symptoms, such as pain, fatigue, appetite, anxiety)
- Memorial Symptom Assessment Scale-Short Form[36] (MSAS-SF; a global scale of distressing symptoms, includes assessment of "distress or bother" for each item)
- Brief Pain Inventory, Short Form[37] (BPI-SF; which includes pain intensity; word descriptors; pain interference with activity, mood, sleep; and a body diagram)
- Patient Health Questionnaire[38] (PHQ; depression screening)
- Distress Thermometer (screening for psychosocial distress; recommended for all patients by the National Comprehensive Cancer Network)[39]

Many clinical practices use a standardized template for palliative care consultation and follow-up visits. The *Serious Illness Conversation Program* has been studied in eliciting patients' preferences for care[40] and can be included as part of the history-taking and charting template to provide an evolving source of information for goals of care discussion.

Funding the Outpatient Palliative Care Program

A practical aspect of clinic viability is the need to secure sources of ongoing funding. Billing revenue is insufficient for ambulatory palliative care programs to become self-sustaining, especially for APRN-led clinics, due to lower reimbursement rates for nonphysician providers.[10,21] Most clinics require institutional support to survive.[3] Other sources of funding include philanthropy, private foundation support, and research grants.[13]

Management by telephone is a major aspect of the provision of outpatient palliative care. Although these calls can make the difference between a patient remaining comfortably at home, rather than making a trip to the emergency department, data on such cost avoidance are difficult to capture.[41] Thus, in some settings, the palliative care team may be challenged to find unique methods to demonstrate to leadership that the palliative care nurse role makes a difference and is not simply another salary expenditure. This may be easier to demonstrate in a managed care setting in which emergency department visits, hospitalizations, and rehabilitation care are paid by the same healthcare system.[2,3] More research is needed to support the cost benefit of outpatient palliative care, especially for the nonreimbursable costs of nursing, social work, and chaplaincy.

Telephone Support and Patient Education

Providing patient support via the telephone is a key function for the palliative care nurse. Prior to the initial visit, the nurse may clarify the role of the palliative care team and the purpose for the referral, then followup after the visit to check on symptom management and distress and to address any concerns. Telephone visits are a source of patient education, encourage adherence to the plan of care, and provide emotional support.

Offering patient education is a core component of nursing care and is a significant focus for the supportive care services. Topics of education may include strategies to address worsening pain and distressing symptoms, tips to improve sleep, steps to reduce anxiety, or methods to prevent and manage constipation. Preparing written materials on these topics will streamline the educational process and is a useful resource for patients and caregivers at home.

Outpatient Palliative Care Needs in Selected Disease States

Palliative care has been most widely studied in the oncology population. However, as the specialty grows, there is an increasing acknowledgment that palliative care, whether primary or specialty, may be beneficial in other disease states. In this section, a brief overview of select disease states that are managed in the outpatient palliative care setting is highlighted.

Oncology

Palliative care has an increasing presence in the ambulatory cancer setting.[13] The 2010 Temel study, with its astonishing findings of improved survival rates and improved QOL despite decreased use of chemotherapy and earlier hospice referrals, firmly established the essential role for outpatient palliative care.[6] Early referral to palliative care for those with a new diagnosis of advanced cancer is recommended by the American Society of Clinical Oncology.[24] Addressing complex pain and symptom management is a frequent consult request for the palliative care team, in addition to assisting with goals of care discussions, EOL planning, and managing psychosocial distress.[11] With the emergence of revolutionary immunotherapies, determination of prognosis has become less dependable in some oncology specialties, such as melanoma, renal cell carcinoma, non-small cell lung cancer, and certain hematological malignancies, thus impacting recommendations and care options during goals of care discussions.[19]

A particular area of need for palliative care services is for patients enrolled in phase I or II oncological studies. Patients tend to have unrealistically high expectations from the investigational agent to achieve a cure or significant improvement in disease control. Most do not understand that the purpose of a phase I study is to determine a drug's safety in humans and a phase II study is to determine safe dosing ranges, but not necessarily trialing more effective therapies. Patients and families often face crushing disappointment when the "new miracle cure" does not work. For this reason, all patients enrolled in phase I or II studies should be offered a referral to outpatient palliative care.[42]

Cardiology

Almost 6 million people in the United States live with heart failure.[22] The course of heart disease is not predictable, and people may experience many exacerbations and hospitalizations prior to death, but about 50% will die within 5 years of diagnosis.[22] Additionally, the prognosis and course have changed due to the increased use of advanced heart therapies.

The American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines for the management of heart failure recommends palliative care for patients with advanced heart failure.[45] In addition, The Center for Medicare and Medicaid Services (CMS) has recommended ACP and involvement of palliative care for those patients who will have LVADs implanted as destination therapy.[46] The Joint Commission also mandates involvement of palliative care for those cardiac centers seeking advanced certification in these therapies.[47] Recognizing that palliative care specialists may not be available in many ambulatory areas, leaders recommend that cardiology practitioners become proficient in providing primary palliative care.[45]

Palliative care in heart failure is a growing field. In a recent, randomized controlled clinical trial, patients who received palliative care in addition to usual care (in both inpatient and outpatient settings) had improved QOL, less depression and anxiety, and improved spiritual well-being. In this study, a certified palliative care APRN coordinated the care in collaboration with a palliative care physician and the cardiology team.[51] In a smaller Canadian study of embedding palliative care into the heart failure team, patient and family satisfaction was improved and there was an increase in ACP.[52] Palliative care was embedded in a heart failure clinic at a large medical center, and, in a retrospective chart review, pain management and ACP were the top two issues addressed, followed by other symptoms often seen in the oncology population. The authors concluded that embedding palliative care in cardiology was feasible.[53] In another study of early palliative care in heart failure conducted at two different medical centers in the northeastern and southeastern United States, patients received an outpatient palliative care consultation followed by nurse phone calls. In this pilot study, patients had improvements in QOL and symptoms and some improvements in hospital stays, intensive care unit admissions, and emergency department visits; however, there were significant differences between the sites in terms of enrollment and attrition, which will necessitate thoughtful application when implementing these programs' processes.[54] Although palliative care in heart failure is in its early stages, experts have concluded that establishing relationships, working with the primary cardiology team in ACP, and providing support and symptom management may benefit those heart failure patients who have complex needs. Additionally, primary palliative care delivered by cardiologists may be the way to move the care upstream (earlier) in the disease trajectory, resulting in improved QOL.[55,56]

Patients with advanced heart failure often experience problematic symptoms secondary to the side effects of the therapy, in addition to disease-related symptoms, and may benefit from the expert symptom management provided by palliative care. Goals of care and EOL care planning can be unique in this population as some patients may utilize intravenous therapies (such as dobutamine and milrinone) to manage symptoms.[57] Even if patients are eligible for hospice, many hospices cannot afford to maintain the patient on intravenous therapy in the home, and there is no consensus as to when to discontinue such therapy.

LVADs are used in two clinical settings: as "bridge therapy" (BT-LVAD) for patients awaiting a heart transplant or as "destination therapy" (DT-LVAD) to extend life and improve symptoms. DT-LVAD was approved in 2003 for those who are not candidates for heart transplant, have severe and worsening heart failure, a life expectancy of less than 2 years, and meet other criteria.[43] As of December 2016, more than 22,000 people have been implanted with LVADs, with half of those implanted for destination therapy by 2015.[44] Recent data indicate that DT-LVAD therapy prolongs life by 15–22 months, with 70% surviving to 24 months in some studies.[44] However, many patients experience significant adverse effects including strokes, bleeding, infection, and device malfunction.

Use of a comprehensive palliative care team (APRNs, physicians, nurse, social worker, and chaplain) is beneficial to increase meaningful understanding of ACP for patients scheduled to receive LVADs. One study found that use of a palliative care consultation style focusing on "preparedness planning" increased family awareness of the importance of ACP prior to LVAD placement and may have influenced EOL decisions.[48]

Although the majority of patients with an LVAD die in the hospital, usually in the intensive care unit,[49] the outpatient palliative care team can assist with preparatory discussions regarding decisions for EOL care. These conversations, which may occur in both inpatient and outpatient settings, include discussions about discontinuation of LVADs and the ethical dilemmas that may surround discontinuation since some clinicians[48] or family members[50] may equate discontinuation of this therapy as euthanasia or suicide. In a survey of 303 clinicians' attitudes toward withdrawal of LVAD support for those approaching end of life, 46% had discontinued LVAD support in two or more patients. Only 26% felt comfortable with discontinuing LVAD support, and 13% considered LVAD discontinuation physician-assisted death.[48] In semi-structured in-depth interviews with bereaved caregivers, 6 of 8 considered LVAD discontinuation as suicide, and one caregiver described discontinuation as murder.[50]

Timing of transition to hospice is impacted in communities where hospice nurses are not familiar with the care of patients with LVADs and may result in a delay in hospice enrollment. The palliative care team can collaborate with the cardiology and local hospice agencies to ensure proper education, including protocols for discontinuation of DT-LVAD therapy.[50]

Another area in which outpatient palliative care can play a crucial role is for those patients with pulmonary hypertension who are not candidates for lung transplant and who require intravenous therapies. In an Internet-based survey, patients reported poor QOL, fatigue, decreased social well-being, and pain. Patients were satisfied with their providers' care of the disease, but not QOL management, and few had been seen by palliative care[58]; thus, an opportunity to improve care exists in this population. Goals of care and EOL care planning can be unique in this population. Most hospices cannot afford to maintain the patient with pulmonary hypertension on the unusually expensive intravenous therapy. Thus, if hospice enrollment is delayed because of intravenous therapy use, outpatient palliative care will be instrumental in managing care until end of life in these cases.

Pulmonology

Chronic lower respiratory diseases are the third leading cause of death in the United States.[59] People with chronic lung disease, such as COPD, may have a longer estimated survival than those with cancer, but they often have severe symptom burdens similar to those with lung cancer.[60] In a retrospective case series of an outpatient palliative clinic for those with COPD ($n = 36$), the topics addressed included ACP, symptoms such as dyspnea and fatigue, and social and psychologic concerns. These patients had significant comorbidities and high symptom burden that had not been addressed prior to a palliative care consultation.[61] Like cardiac disease, these illnesses are chronic and are often marked with exacerbations, hospitalizations, a decline in function over time, and an uncertain prognosis. As the disease progresses, patients face choices about the use of noninvasive or mechanical ventilation. In a study of pulmonologists in the Netherlands, there was no consensus about when to refer to palliative care. The pulmonologists indicated the need for ACP, the need for identification of the "palliative phase," and the need for communication with the primary care providers.[62] Phillip and colleagues, through the evaluation of qualitative and cohort data, formulated recommendations for palliative care delivery for COPD in Australia.[63] They recommend triggering a palliative care consultation during clinical transitions, regardless of symptoms or prognosis, and embedding palliative care into the ambulatory care setting. The tasks defined for the palliative care team were similar to those seen in other disease states—symptom management, support for patient and family, and goals of care decisions.[63] Although there is limited research, based on findings from other disease states, palliative care integration into the ambulatory setting may improve symptom management and QOL for those with advanced pulmonary illnesses.

Nephrology

By the end of 2016, more than 700,000 people had ESRD, and almost 500,000 people with ESRD were undergoing renal replacement therapy (dialysis) in the United States, and more than 100,000 are older than 75 years.[64] People with ESRD often have significant symptoms and comorbid conditions affecting QOL. Although research is still needed, there is a growing awareness of the need to integrate palliative care into this population.[65,66] A major decision in ESRD is whether to initiate or discontinue dialysis. In a study that analyzed survival in patients older than 70 years with ESRD who either chose renal replacement therapy or conservative therapy, those older than 80 who had multiple comorbidities and received renal replacement therapy did not survive longer than those who chose conservative management. Seventy-six percent of those in the conservative management group received palliative care services compared to none in the renal replacement group. Those receiving palliative care were less likely to be hospitalized or die in the hospital.[67] Thus, even though the research in nephrology is still in its nascent stages, outpatient palliative care involvement may improve symptom management and QOL while addressing goals of care and ACP needs.

Neuromuscular Diseases

Those living with ALS have a vital need for supportive care services. ALS is a life-limiting illness in which ACP and goals of care are essential as patients must face decisions related to initiation of enteral feeding and, ultimately, respiratory support. Although experts agree that palliative care involvement is recommended, the integration of it is variable.[18,68] Palliative care specialists partnering with patients in shared decision-making should possess knowledge about the issues unique to this population to best assist with complex decision-making and symptom management.[69,70] For example, early placement of a feeding tube is preferred as a means to improve QOL by maintaining hydration and nutrition, and noninvasive positive-pressure ventilatory support is the standard of care, rather than invasive mechanical ventilation.[69]

The integration of palliative care may be best accomplished by embedding a palliative care specialist in the clinic as patients often come for half-day sessions to see all the specialists involved in their care (neurology, rehabilitation medicine, occupational and speech therapy) as a way to conserve the patient's energy. Neuromuscular disease is an ideal setting to provide enhanced primary palliative care. Nurses and APRNs working in ALS clinics may seek additional education and certification in palliative care, thus creating the ability to address the disease-specific needs as well as palliative care needs of this unique patient population.

Gerontology

The baby boom generation is aging. According to the Center for Disease Control and Prevention (CDC), every day between 2011 and 2030, 10,000 persons are turning 65-years-old in America.[1] By 2030, one in five (20%) adults will be an elder. This unprecedented wave of older adults, known as the "Silver Tsunami," will have a significant impact on palliative care in the ambulatory setting. Goals of care decisions may be complex in the geriatric setting, in which high symptom burden is juxtaposed with increased risk of poor outcomes, decreased tolerance to physical stress of procedures, and limited life expectancy[71,72]

Consults to the outpatient palliative care team may be generated with the initial diagnosis of dementia to assist with complex ACP. These deliberations are important to have in the early stages of debility, when a patient still has decisional capacity and can clearly state his or her wishes.[73] The American Geriatrics Society has a variety of publications applicable to palliative care specialists, including a position statement on the use of feeding tubes in advanced dementia.[74]

When working with elders, it is essential to provide individualized care and not make assumptions about preparedness for death based on age alone. For example, a 94-year-old patient is deemed too frail to undergo a transcatheter aortic valve replacement (TAVR) for improved QOL.[75] Despite being quite old, news of this decision may abruptly thrust the elder into existential crisis by a sudden realization of advancing age, frailty, and approaching death. Compassion and sensitivity by the palliative care team will aid with coping and encourage completion of needed preparations for eventual demise.

Managing Opioid Analgesics, Benzodiazepines, and Other Controlled Substances in the Outpatient Palliative Care Setting

Opioid analgesics, benzodiazepines, and stimulants are essential for pain and symptom management in palliative care. Given the high utilization of these medications in advanced disease, especially in oncology, healthcare teams have an obligation to institute strategies to maintain safety and prevent abuse and diversion in order to ensure ongoing and appropriate access to these vital pharmacological therapies.[76] Although some may question the necessity for screening and monitoring of patients on controlled substances in the palliative care setting, it is clearly needed given the current epidemic of opioid-related deaths in America.[77,78]

In 2016, 29 million (or 1 in 10) Americans ages 12 or older used an illicit drug within the previous month surveyed, and more than 20 million people in the United States had a substance use disorder (SUD).[79] Importantly, patients with cancer screened for substance abuse risk had similar risk characteristics as those with chronic nonmalignant pain,[80–83] with estimates that 1 in 5 cancer patients are at risk of opioid use disorder.[84] Additionally, more than 65% of persons who abuse opioids bought, took, or were given them from family members or friends with a legitimate prescription.[85] Such diversion may put the patient at risk for inexplicably running out of medications early and developing acute opioid or benzodiazepine withdrawal.[86]

When a person with a current or former SUD develops a life-limiting illness, it is not uncommon for maladaptive coping strategies to emerge. "Chemical coping" is a term used to describe those who use opioids or other substances to try to deal with the stress associated with diagnosis or progression of disease.[87] In a prospective study of 432 patients with advanced cancer, 18%, or nearly 1 in 5, were diagnosed as chemical copers.[87] An additional form of prescription drug abuse involves patients or caregivers selling their prescription drugs as a means to supplement lost income due to illness. Medications that are not stored safely, such a partially used fentanyl oralet, may expose children or pets to overdose death. Because of the abundance of opioids, benzodiazepines, and stimulants in the outpatient palliative care setting, strategies are needed to assess and monitor patients receiving these drugs.

Universal precautions in pain medicine is a strategy advanced by Gourlay and Heit for chronic noncancer pain and is based on the concept of universal precautions used in infectious disease.[88] Similarly, every person receiving an opioid or other controlled substance should be screened for risk of drug misuse and regularly monitored. Such screening does not imply that a person with a history of drug abuse cannot receive opioid therapy to manage pain or dyspnea. Rather, these are tools to help to identify those who would benefit from additional safety monitoring, and informs the prescribing process.[89,90] Components of universal precautions include assessment of risk for substance misuse, informed consent, treatment agreements, urine drug screening, and review of the state prescription drug monitoring program. These guidelines have been successfully adopted in outpatient palliative care clinics.[80,82] Patients and caregivers are more accepting of screening and monitoring when informed that they are universally applied, "just like TSA screening at the airport." Nurses play a key role in assisting with the patient screening and follow-up in terms of tracking analgesic use and educating patients on safe use, storage, and disposal of opioid analgesics.[91,92] See Box 52.2 for additional details on universal precautions when prescribing controlled substances. Table 52.1 provides example guidelines for using risk stratification to determine the intensity of monitoring that may be required in the outpatient palliative care setting.

Treating cancer-related pain with multimodal analgesia is the foundation for safe and effective pain management and has been recommended by leaders in cancer care.[93,94] Nurses can be strong advocates for inclusion of nonpharmacological and complementary therapies to manage pain, anxiety, and insomnia as an alternate to relying only on controlled substances.[95] Alternate therapies are especially important considerations in the growing geriatric population, who have a narrow therapeutic window of safety with controlled substances.[96,97]

Finally, the highly publicized epidemic of opioid-related deaths in America has made many patients even more fearful of utilizing prescribed opioids for the management of pain from advanced cancer or other conditions. Nurses in the outpatient palliative setting are in a strategic position to educate patients on the appropriateness of using opioids to manage pain from a life-limiting illness.

Conclusion

This is an exciting time of momentum in the field of outpatient palliative care. As the discipline grows and matures, attention is turning toward clinics with large numbers of patients with serious illness such as cardiology, pulmonology, nephrology, neurology, and geriatrics. The imperative of reducing healthcare costs can be positively impacted by outpatient palliative care in reducing emergency department visits and hospital admissions and readmissions.

Because there are more patients than can be seen by the limited palliative care resources, use of screening methods should be utilized to identify those who are in the greatest need of referral. For the remainder, clinicians and nurses must learn the skills for providing primary palliative care in the outpatient setting.

Nurses play an important role in the provision of outpatient palliative care, with research showing that nurses and APRNs provide much of the staffing in these settings. Nursing skills are well-adapted for issues commonly addressed by the palliative care team. With additional training in programs such as End-of-Life Nursing Education Consortium (ELNEC), every nurse can indeed become a palliative care nurse.[101]

Box 52.2 Best Practices for Opioid and Other Controlled Substance Prescribing in Outpatient Palliative Care

Practice universal precautions: All palliative care patients receiving opioids and other *Controlled substances* should be approached using these criteria.

1. Utilize a screening tool (such as the Opioid Risk Tool [ORT][99] or Screener and Opioid Assessment for Patients with Pain—Revised [SOAPP-R][100]) to identify individuals at increased risk for drug misuse or abuse.
2. Review the state prescription drug monitoring program (PDMP) before each prescription for a controlled substance.
3. Complete a patient-provider treatment agreement to clearly delineate expectations.
4. Consider urine drug testing at baseline and at least annually thereafter.
5. Specify maximum daily or monthly usage (e.g., "maximum 3 tabs per day," or "must last 30 days") or inclusion dates on the prescription.
6. Consider prescribing naloxone for emergency home reversal of opioid overdose, per CDC guidelines, when the prescribed morphine equivalent daily dose is more than 50 mg/day.
7. Continue to evaluate risks at each visit because they may change over time.
8. Educate patient and family about safe storage, administration, and disposal.
9. Educate patient and family on what to do in the event of adverse side effects from opioids.

Source: From References 76–78, 84, 86, 88–92.

Case Study: A Patient with an LVAD

Ron was a 56-year-old single man who lived a comfortable life in a large city. He worked in the arts and had an active social life. He was independent and had many acquaintances but no significant social support. He had a small family, with only a sister who lived across the country. He had survived testicular cancer that afflicted him in his early twenties. Ron did not attend to his medical care and was completely unprepared when he suffered a myocardial infarction and developed severe heart failure. He was told he needed a heart transplant and that LVAD implantation would improve his symptoms while he waited for the transplant. Prior to the LVAD implantation, he met with the palliative care APRN and social worker. He completed his advance directives and made plans to continue visits with the palliative care team as he was experiencing significant psychosocial distress. Six months after the LVAD transplant, Ron began experiencing indigestion, back pain, and weight loss. After multiple visits to the emergency department, he underwent a scan, which showed a pancreatic mass with liver involvement. Life again changed for him as he now had to deal with the fact that he had an incurable cancer and that he would never have a heart transplant. After meeting with the oncology team, he agreed to start chemotherapy, but quickly

Table 52.1 Opioid management guidelines and risk stratification for outpatient palliative care

Universal screening of all patients			
Baseline screening at first or second palliative care visit.	1. PDMP review 2. SOAPP-R 3. Calculate and document MEDD 4. Controlled Substances treatment agreement signed, scanned, original to patient 5. Urine drug testing 6. Risk stratification determination.		
Criteria for risk stratification	Clinically assessed low risk, SOAPP-R ≤ 9, and MEDD <100 mg	Clinically assessed medium risk, SOAPP-R 10-21, or MEDD ≥100 mg	Clinically assessed high risk or SOAPP-R >22
Risk stratification potential for opioid misuse	Low ("standard")	Medium	High
Palliative care social worker participation in care	Provider discretion	Joint visit provider and social work at next appointment and at future visits as needed	Joint visits provider and social work at all future visits
Additional monitoring and consultations	Provider discretion	Provider discretion	Consider additional consult services (addictionology, psychiatry); additional monitoring at provider's discretion
Follow-up visit (minimum frequency)	Every 1–3 months	Every 1–2 months	Every 2 weeks until adherence is established, then minimum of every month thereafter
UDT (minimum frequency)	Annually	Every 6 months	Every 3 months
PDMP	Before each visit and each Rx renewal	Before each visit and each Rx renewal	Before each visit and each Rx renewal
MEDD calculation	Every visit	Every visit	Every visit
Pill count	Optional	Consider, random	Consider, random or every visit
Naloxone nasal spray[a]	Consider offering prescription (based on comorbidities)	Consider offering prescription	Offer prescription
Pain diary[b]	Optional	Optional	Yes

MEDD, morphine equivalent daily dose; PDMP, prescription drug monitoring program; SOAPP-R, Screener and Opioid Assessment for Patients with Pain—Revised[100]; UDT, urine drug testing.

[a] Naloxone nasal spray per CDC guidelines, to emergently reverse opioid overdose in the home setting, indicated for those receiving morphine equivalent daily dose of 50 mg or higher and for individuals at higher risk of opioid overdose at lower MEDD.[77]

[b] Used to track patient use of *as needed* opioid doses.

Source: From References 77, 86, 89, 90.

Adapted from Matthew M. Wilson, MD, *Dartmouth Hitchcock Medical Center, Section of Palliative Medicine, Opioid Management Guidelines*, September 28, 2016. Used with permission.

developed worsening symptoms. The palliative care APRN and social worker worked to manage his increasing symptom burden. Ron developed increased despair as he became more limited in his activities and ultimately decided to forego further chemotherapy. He was conflicted because, although he knew he could decide to discontinue the LVAD therapy, he was afraid to end his life in this manner. His sister came to visit and also felt helpless to provide care. The palliative care team met frequently with them to provide support and work on EOL care planning. Ultimately, Ron went to live in a residential hospice facility. The palliative care team initiated support from the cardiac team to train the hospice nurses in the care of the LVAD until Ron's death. The multispecialty coordination, championed by the outpatient palliative care team, allowed for improved symptom management for Ron in his final days and weeks of life.

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CHAPTER 53

Palliative Care in the Emergency Department

Rebecca Wright and Benjamin Roberts

Key Points

- Palliative care is still an evolving specialty in the emergency room (ED), requiring further research and development of tailored, interdisciplinary training and education programs and care processes.
- Research has demonstrated that safe and effective delivery of ED-based palliative care is possible, with growing numbers of tools and models to support care delivery and goals of care conversations.
- Community-based nurses and other healthcare professionals involved in referring patients with palliative care needs to the ED should encourage use of advance directives or documented care plans to support shared decision-making and treatment congruent with patient wishes.
- Once in the ED, assessments for patients with long-term, incurable conditions should also address palliative care needs, including social, spiritual, and family needs.
- An ED visit can provide an opportunity to identify unmet or exacerbated palliative care needs for patients and families.

Introduction

The emergency department (ED) is not typically associated with palliative care. The traditional model of "resuscitate, stabilize, transfer" is seemingly at odds with the holistic, in-depth approach of palliative care. This is emphasized by the use of ED visits and acute care utilization as an indicator for poor outcomes and failures in coordinated, community-based care.[1] However, despite efforts to reduce ED visits and return visits by improving provision of palliative care in community settings, a significant number of people with palliative care needs continue to visit the ED in times of crisis, viewing it as a "safety net."[2] Further complicating matters are the growing complexities of caring for an aging population with comorbidities, meaning that some ED visits may be due to underlying, complicated palliative care needs.[3]

The ED serves as the gateway for access to healthcare for many people, and there is a growing consensus that it can and should play a vital role in the provision of palliative care.[4] Despite many challenges, the ED represents a place of safety and refuge in times of crisis. People with complex and unpredictable conditions, along with those who may struggle to access healthcare due to financial challenges and inequalities in healthcare access, particularly benefit. Nurses have a responsibility to work with the ED and support ED clinicians to provide palliative care in what often represents the most distressing times of illnesses.

This chapter presents the epidemiology of palliative care patients who use the ED and reviews the main barriers to provision of ED-based palliative care, drawing on published examples of patient and clinician experiences. These barriers are addressed by outlining facilitators to ED-based palliative care including new models, approaches, and tools. The role of the ED within the wider healthcare context of palliative care is emphasized. To illustrate the challenges for clinicians caring for palliative care patients in the ED and how to address them, a three-part case study will be presented with practice-based discussion points.

Epidemiology: Incidence, Prevalence, Causes

There are limited data regarding the incidence and nature of ED patients with palliative care needs, along with a lack of a uniform definition of palliative care in the ED setting. This presents a challenge in generalizing a clear concept of the ED patient with palliative care needs.[4,5] For example, numerous site-specific studies present a wide variety of information regarding the demographics and characteristics of ED patients with palliative care needs, including gender, race, and disease.[4] A small body of qualitative research exploring the experiences of palliative care patients seen in the ED identified common themes triggering visits (see the section "Needs and Experiences of the Palliative Care Patient"). These included uncontrollable symptom burden and inability to cope at home[6] and inability to access or lack of access to community-based care services.[2] Lack of access to care and financial reasons were noted particularly for minority populations in the United States.[7] In some cases, patients were directed to the ED by their community providers, for example, cancer patients receiving chemotherapy in response to a spiking temperature.[2] The notion of the ED as a safety net in times of crisis was raised by patients with some relief, but with the caveat that there was also no alternative.[2]

Patients admitted to the ED who then receive palliative care consultation present with a wide variety of traits and conditions. It is critical to reach consensus about these traits in order to identify palliative care needs and provide timely care.[5] This is particularly important given an increasing usage of the ED by patients with palliative care needs.[4] Complicated factors must be addressed; for example, data suggesting different conditions, such as cancer and chronic obstructive pulmonary disease (COPD), have different drivers for ED visits, different palliative care needs, and report different experiences.[2,6]

Still, studies suggest certain trends, such as a common need for symptom management and life-prolonging interventions.[4] Green et al. (2016) found that, within a large urban hospital, the leading causes of ED visits by people with palliative care needs were shortness of breath and pain. Other common complaints included falls, neurological symptoms, nausea and vomiting, fever, dehydration, diarrhea, and fatigue.[8] However, a clear distinction was made to differentiate between these presenting symptoms and the "underlying palliative conditions," such as cancer, COPD, and dementia.[8] Not all palliative care admissions are from complicated causes; in some cases, the reason for the visit are classified as a "palliative emergency"; these are instances occurring in patients with an incurable condition that will lead to death or decreased quality of life (QOL). Common palliative emergencies include uncontrolled pain, acute dyspnea, hemorrhage, hypercalcemia, acute anxiety, and acute loss of function.[9]

Some of these trends span continents. For example, a high incidence of cancer-related health problems, as well as age greater than 60 years, was found to be common across a rural setting in New Zealand and an urban academic medical center in the United States.[10,11] Taken together, especially in light of increased ED utilization in the final 12 months of life, the palliative care needs of the ED patient emerge.

Drawing this information into the first of a three-part case study, Part 1 highlights the issues outlined in a common ED visit from a patient with underlying palliative care needs. The barriers and facilitators to integration of palliative care in the ED are introduced.

Case Study: A Patient in the ED–Part 1

MB is a 72-year-old Spanish-speaking woman who presented to the ED from home in respiratory distress, with a chief complaint of shortness of breath. Her past medical history revealed COPD, right-sided recurrent pulmonary effusion with repeated episodes of pneumonia, left ventricular heart failure (LVHF) with right ejection fraction (rEF) to 15%, poorly managed type 2 diabetes, arthritis to bilateral knees and hands, depression, and chronic severe pain to the lower back. MB lives with her husband of the same age, who was able to help her with basic activities of daily living (ADLs) but was often too weak or exhausted to manage his own health issues as well as his wife's. MB could afford to be visited once a week by a home health aide who was able to assist with medical management, daily cares, and provide some degree of emotional support to both MB and her husband. Most days, however, errors were made in her medication regimen, hygiene was minimal, and MB felt "too frail and depressed" to pursue her lifelong passion of photography. Most days, she did not go outside. She has had five visits to the ED over this past year, which was an increase from three the previous year and only one the year prior.

In the ED, her SaO_2 began to rapidly decline, and she became tachypneic, tachycardic, and hypotensive. The ED providers ordered multiple large-bore intravenous placements, bolus fluids, stat blood gasses, and 100% nonrebreather facemask. MB was afraid, in tremendous pain, confused, and felt unable to speak. Her husband had not yet arrived, and there were no advance directives (ADs) in place. A chest x-ray revealed right-sided pneumothorax and possible pleural effusion. A chest tube was inserted emergently at bedside, and both fluid and air escaped. Only 5 cc of a local analgesia was administered subcutaneously—no systemic pain control was considered. As the team discussed emergent intubation, her SaO2 began to stabilize at roughly 90%, her breathing became less labored, and she became more alert and calmer.

Discussion Points

Barriers to palliative care:

- Adequate care at home for frail individuals is expensive and often unavailable, leading to loss of ability to accomplish daily tasks and participate in activities of passion and enjoyment and increased depression.
- The standard ED model focuses on life-saving care, paying less attention to alleviating suffering and increasing QOL.
- There are no advance directives in place to speak for the patient when the patient cannot speak for herself and her proxy is not yet present.

Ways to integrate palliative care:

- In the case study, notice the recent increase in visits to the ED in the past year. Each ED can pay careful attention to frequent visits, particularly for patients suffering from life-limiting illness, and create automatic triggers for palliative care referral and delivery for these patients.
- Every visit to the ED is an opportunity for education about advance directives and advance care planning. No one near the end of life need leave the ED for the fifth time in 1 year without a documented patient-centered care plan.
- If emergency procedures such as chest tube insertion are to be carried out, the administration of sufficient systemic and local analgesia can be prioritized for the patient with palliative care needs.

Barriers and Challenges to ED Palliative Care

Having outlined the triggers for an ED visit and demonstrated the need for a palliative care-prepared ED, the following is a discussion of the issues that prevent high-quality palliative care delivery. It is important to understand these barriers for effective integration of palliative care into the ED. Current barriers include, but are not limited to, the traditional ED model of care delivery and care processes, the physical environment, and changes in the clinical presentations of the population served by the ED. Patient, family caregiver, and clinician experiences are also reviewed because an understanding of their perceptions enables better understanding of how to tailor strategies and implement new models of care to address issues specific to palliative care populations.

The Current ED Model

The ED is a time-sensitive environment, influencing hospital admission and discharge rates and serving as the gateway to healthcare for many people in times of crisis.[12] The current ED emerged from the "casualty" model employed on battlefields, where saving lives was the focus.[13] While there are many successful stories of ED-based palliative care,[14,15] the ED model of care still largely retains the "triage, resuscitate, stabilize, transfer" approach. The "resuscitate, stabilize" focus poses a challenge to ED clinicians when caring for patients with complex needs who require a more holistic and broader assessment.[5] Even when faced with palliative emergencies, ED clinicians require an understanding of the underlying trajectory and plan of care to conduct necessary conversations with patients and families and rapidly focus or refocus treatments.[9] Clinicians require training and education to refocus on symptom control and QOL over life-sustaining measures. As discussed later, this can be acutely distressing for ED clinicians who can feel they are not "doing enough."[16]

The ED model extends to the physical environment, and here, too, there are challenges for delivery of palliative care. In line with the need for practical and immediate, unplanned emergent care, the majority of EDs are brightly lit and contain different treatment areas according to severity of patient need (e.g., minor and major injuries and resuscitation). Even in modern EDs, space is often limited and lacking in privacy.[17] High patient numbers, distressing conditions and sounds, and a constant flow of patients and staff result in a noisy environment. The ED functions as a streamlined department in which its clinicians are highly trained and operating within routines and standardized procedures. However, to many patients, particularly those who are more vulnerable, the constant movement and noise can make it appear chaotic and unorganized.[17] This can exacerbate tensions and concerns for palliative care patients and families whose needs may be prioritized below other more obviously acutely ill patients.[16,18] Indeed, some palliative patients report feeling that they are competing for attention against other patients (see the section "Needs and Experiences of the Palliative Care Patient").

Palliative Care–Specific Patient Complexities

"Traditional" ED patients can be classified as those experiencing "spectacular" medical or surgical crises (e.g., myocardial infarction, shortness of breath, road traffic accidents, falls, and other injuries).[18] However, advances in healthcare delivery, treatments, and improved QOL have seen people living longer with multiple conditions.[19] Some community programs and resources are available but, as highlighted, people may not be connected to them or are unable to access them.[8] As a result, ED clinicians increasingly care for patients with "subtacular" needs.[18] Coined by Bailey, subtacular patients in the ED include those with end-of-life (EOL) or hospice care needs, nontraditional palliative emergencies, and complex psychosocial needs as people approach the end of life.

Clinicians also need to be careful to retain an individual, holistic approach, recognizing different patterns across conditions. Patients with cancer may be more likely to attend the ED having tried alternative routes first, whereas people with COPD may be more likely to bypass other services and seek out emergency care, ensuring that they carry pertinent information with them.[6] Additional complications for ED clinicians trying to identify palliative care needs include multiple conditions, different condition trajectories, and underlying palliative needs not immediately identified in the presenting complaint.[11] In many of these cases, a major barrier is the lack of preexisting clinician–patient relationships.[18] When faced with complicated family relationships and patients with varying degrees of cognition, clinicians may struggle to identify patient goals and preferred care. Many clinicians avoid these complex discussions with patients.[18] Furthermore, use of ADs is not systematically employed, meaning that patients may not have participated in advance care planning or may not know to alert ED clinicians to the existence of this information. This and other gaps in communication between patient, family, and provider lead to worsened outcomes and conflict surrounding life-sustaining interventions (see the section "Clinician Training and Perceptions").[16]

Needs and Experiences of the Palliative Care Patient

Palliative care research and services aim to support patients and families by identifying and working to meet their goals and preferences. However, there are limited data exploring ED-specific preferences and experiences. This is likely due to the inherent ethical and practical challenges of conducting palliative care research with a vulnerable population in a challenging environment.[20–22] To date, a small number of qualitative studies have sought to explore patient and family caregiver perspectives. Studies reflect a global interest in the patient experience, providing findings predominantly from the United Kingdom,[6,21,23] the United States,[15,24–26] and Australia.[2] Interestingly, the ED structure is consistent across numerous countries and healthcare systems, with similar patient-family experiences reflected throughout.

Patient and family experiences in the ED and their reactions to palliative care measures fall broadly into "positive" and "negative" categories, with patients expressing a mixture of "anxiety, uncertainty and relief."[2] Clinicians sending patients to the ED or admitting and caring for them should be aware that the ED can be seen as either a place of reassuring assistance or a regretfully unavoidable outcome.[21] The ED environment, in addition to being challenging for delivery of palliative care, has also been cited as hectic and overwhelming.[2] Factors increasing uncertainty are particularly distressing, such as long wait times and a lack of clarity regarding referral processes and navigation between settings.[6,16] Some patients and family caregivers noted that ED care focused more on diagnostics than on symptom management.[2] Patients who recount positive experiences of using the ED when experiencing palliative care needs highlight "soft skill measures," such as communication about wait times and ED processes that were impactful in reducing anxiety.[6,21] Given that symptom control is a major reason for use of the ED, this is a key area for staff training and education in palliative care assessment. Indeed, it may be beneficial to introduce palliative care measures, such as consults or other supportive measures, during long wait times to alleviate distress and promote progress with care planning.[6]

When palliative care was provided, the integration of care sometimes caused concerns when ED staff lacked the training to implement specific measures (e.g., higher medication doses and more frequent administration of analgesics).[16] When reflecting on ED-initiated referrals to palliative care services or seeing palliative care clinicians in the ED, patients and families had varying responses depending on their familiarity and understanding of palliative care.[27] Prior knowledge of palliative care meant less concern. General misunderstandings of palliative care can lead some patients to relate it directly to EOL care and a sense of "giving up."[27]

Notably, patients with palliative care needs or certain conditions (such as cancer) may see themselves as being different from other patients due to the severity of their conditions.[27] Coming to the ED meant they needed help but did not mean they wanted all possible treatments.[6] Clinicians should note that this emphasizes the need and opportunity for shared decision-making.[28] Often patients were dealing with their reactions to the intense environment of the ED in conjunction with the changes in their physical condition and personal lives. When considering goals of care, ED clinicians can be mindful that palliative care patients and family caregivers are grappling with multiple changes. The ED visit may often represent unplanned or unmanageable changes in condition, capacity, or disease trajectory, thus triggering further anxiety.[21] Patients with cancer or older patients were most concerned about the potential implications of the ED visit (death, irreversible decline),[6,29] whereas patients with COPD were more likely to find the environment reassuring and be more familiar with the documentation needed to ensure appropriate care.[6]

The implications affect both the patient and the informal caregiver. Clinicians should include caregiver needs as part of their assessment, not least because of their pivotal role as a major source of support and reassurance.[2,21] This role is emphasized in the ED, where caregivers often help maintain a sense of normalcy for the patient.[6] Thus, while the ED may represent a decline in condition or caregiver capacity to cope at home, the visit provides opportunity for assessment of caregiver burden and referral to support or palliative care services while acknowledging and validating their role.

Clinician Training and Perceptions

Clinician buy-in is essential if palliative care is to be routinely offered in the ED. Palliative care ED training and education for physicians has been developing since the implementation of co-certification in palliative and emergency medicine in the United States in 2006. Importantly for nurses, there is still no standardized certification in ED-based palliative care, although the End-of-Life Nursing Education Consortium (ELNEC) training program does include the ED.[30] While there are a small number of palliative care ED training modules available,[31] most focus on doctors.[3,32] While these are important programs, the lack of inclusion of an interdisciplinary team (IDT) jeopardizes the opportunity for the collaborative work required for both palliative and ED care. Often, nurses and physicians will seek out palliative care training[33] because standardized palliative care education and training is not routinely provided in most EDs. Generic palliative care training may address emergencies, but does not routinely equip clinicians to engage in smooth transfer and care delivery processes. Few programs address some of the more unique challenges of the ED whose solutions will not be possible to implement, despite inventive adaptation. There remains a need for standardized, tailored, IDT, ED-based palliative care training.

In response to the increased presence of palliative patients in the ED and the initiation of palliative care as a subspecialty of emergency medicine, several small-scale qualitative studies have explored ED clinician experiences, perceptions, and beliefs about the provision of ED-based palliative care.[33,34] Again, the focus is predominantly doctors and/or nurses, with very limited inclusion of other members of the IDT (e.g., social workers[35] and administrators[24]). Rarely do studies examine multiple members of the IDT together.[21,34]

Studies have found a mixed response from ED staff considering palliative care. Resistance to palliative care often stems from the desire to provide the best care for patients and concerns that the ED should not encourage palliative care patient visits because it may not be the best location in which to treat such patients.[34] Limited time and space and noise were often cited as barriers to delivery of palliative care by ED clinicians.[33] Some stated that, even if it were appropriate, integration of palliative care into the existing model would be too costly and challenging.[34] Those in favor of integrating palliative care state that it is a core part of the role of the ED and that the ED at its core must respond to the needs of the patients who are seeking care.[36] These clinicians are often highly skilled in palliative care delivery or have a particular interest in the topic. However, even among those in favor of integration of palliative care into the ED, there were concerns about the ability of providers to offer the type of care required under current conditions. Given the algorithmic approach to patient care that supports the ED model, a lack of clarity in such a vital aspect of healthcare delivery must be addressed to support the practice of ED clinicians.

As with patient and family experiences, ED clinicians have witnessed a variety of positive and negative experiences. Beyond these personal experiences, additional challenges include difficulty accessing key information when patients are admitted from the community (e.g., ADs and goals of care).[25,33] ED clinicians expressed concern that care is impeded by limited access to palliative care teams, particularly outside of normal working hours.[25,36] These reflections were tied to a common theme of role confusion over palliative care delivery, questions about who should implement palliative care, and if it is part of the role of the ED clinician at all.[33] The frequency of role confusion in several studies suggests this is an area for focus in ED-based palliative care training and education, where clarifications and agreed processes can support practice. Embedded in this role confusion is an issue of significant concern: that there continues to be a lack of agreement and understanding of *what* palliative care actually is.[33,34]

Considering their clinical practice and values, the life-saving focus of the ED means that some ED clinicians struggle with the underlying concepts of palliative care. For some, palliative care means giving up or betraying their patients by taking alternative courses of action that focus on QOL and symptom management as opposed to full resuscitation measures.[16] This sentiment is exacerbated in instances where patients are unknown to ED staff.[16] Inpatient and community nurses can play an important role in supporting ED clinicians, for example by educating patients and families about what information is required if an emergency visit occurs. This can include completing ADs and care plans with contact details for core care providers that patients can carry with them should they require ED services. A more integrated community ED could also support those ED clinicians who may be reluctant to look beyond the immediate presenting cause. Such actions can be particularly useful in instances when ED clinicians may be reluctant to question current treatment regimes even when verbally requested by patients and families.[16] Standardized or easily accessible documentation could also improve the quality of difficult conversations between ED staff and medical teams overseeing some patients and between ED staff and patients/families.

Limited Knowledge and Research

Increased recognition of patients with palliative and end-of-life needs in the ED has encouraged a growing field of research and study. Much of this work is still in exploratory stages,[28,33,37,38] and there is much to understand in terms of generalizing prevalence and incidents rates.[4,39] As outlined earlier, a handful of small-scale qualitative studies have provided valuable insight into clinician perceptions and experiences, but these tend not to have an IDT focus. Patient- and family caregiver–centered research is gradually increasing but tends to focus on patients with cancer.[2,40–43]

Numerous ethical and feasibility challenges can deter researchers and impact the validity of quantitative research, while some may deem qualitative research overly draining or inappropriate for patients at the end of life.[44] Ultimately, in both clinician and patient–family populations, a limited body of research has moved beyond exploration of perceptions and experiences, although this rich source of data can provide a foundation on which to build. A small number of more rigorous studies have studied the impact of palliative care measures implemented into the ED which demonstrate feasibility and impact (see the section "Facilitators to ED Palliative Care").[14,45] Sadly, patient and family caregiver involvement remains limited, thus decreasing the generalizability and applicability of new models. Certainly, the current body of knowledge is not yet broad or rigorous enough to conduct comparative effectiveness trials to inform evidence-based best practice guidelines. However, the development of consensus statements and research agendas is beginning to address different aspects of ED-based palliative care, for example, shared decision-making.[28]

To demonstrate the practical implications of these barriers, Part 2 of the case study demonstrates how different approaches to and understandings of palliative care among ED clinicians can confuse and affect the trajectory of a patient's condition. The value in written documentation to support shared decision-making processes is highlighted.

Case Study: A Patient in the ED–Part 2

The resident leading the response to MB's respiratory distress told MB that she needed mechanical ventilation if she continued to desaturate. MB was not entirely sure what it meant to be on a respirator. English was not her native language, and she did not know what "mechanical ventilation" meant, but she agreed to the resident's recommendation. Then, MB's husband arrived and he explained to the primary RN that MB wanted never to be intubated. The RN asked the husband if there were any written ADs and the husband said there were not. The RN then said, "Until we have that, we have to do everything we can to save your wife." The husband sat with his wife, who continued to stabilize, and held her hand. "I don't want to live if I'm going to live like this," she told him. The husband found the resident and relayed this message. The resident replied, "We are doing everything we can for your wife—she is in very good hands. As you can see, she is already in better condition than she arrived in." Another RN overheard this conversation and asked the husband if he had ever heard of palliative care. The husband said, "No, but he had heard of hospice," and asked if MB might need hospice care. The RN approached the resident and stated, "MB and her husband are not on board with aggressive treatments. Can you order a palliative care consult?" The resident looked at MB, saw her slowly rising SaO_2, and said, "Are you kidding, look at her! We've got her stabilized, we can send her to the floor in no time."

Discussion Points

Barriers to palliative care:

- The lack of patient-centered communication and shared decision-making led MB to agree to a procedure she had previously determined she did not want. Language barriers and health literacy issues may be present in addition to difficulty understanding medical jargon.
- The ED practitioners are unable or unwilling to accept verbal desires about treatment limitations in lieu of formal ADs. In an emergency, the absence of ADs could lead to unwanted interventions.
- Because of the standard ED model's focus on life-saving and the myth of palliative care as being only useful for actively dying patients, the resident does not see the utility of a palliative care consult for a patient whose emergency is improving.

Facilitators to palliative care:

- The second RN is able to talk with the family and patient about their treatment goals and introduces the possibility of palliative care.
- This RN is willing to ask the doctor to order a palliative care consult, even though he shows resistance.

Ways to integrate palliative care:

- ED providers can communicate with their patients in clear, nonmedical terms and ask for teach-back to ensure the patient understands. Furthermore, patients who speak a foreign language must be offered formal interpreter services, especially during consenting procedures.
- ED providers can clearly document any preferences and concerns raised by patients to support their transfer and future care.
- The ED can incorporate nurse-managed palliative care consult orders to avoid the difficult situation of convincing a doctor that palliative care is necessary. With standardized education, all practitioners will have a better sense of when palliative care is appropriate. However, nurses are on the front line of patient advocacy and are in a prime position to ensure palliative care delivery is timely and effective.

Facilitators to ED Palliative Care

Despite the barriers to ED palliative care, a number of commonalities between the two specialties demonstrate the capacity and potential for integration. Both deal with highly emotive interactions and provide for care of patients of all ages, many with a variety of chronic or life-threatening diseases, often focusing on controlling the presenting and distressing symptoms or cause.[15] Over the past decade, researchers, policymakers, and palliative care and ED clinicians have sought to develop and test different models, approaches, and tools to provide for patients with palliative care needs in the ED. This process is still in its infancy, and currently there is no consensus on the most effective mechanisms for integration.[14] This marks a key challenge for nurses working in and outside of the ED to know how best to support patients and facilitate smooth and appropriate transfers and referrals. Small review studies have now begun to collate the research literature in order to analyze the effects of different models. Thus, while there are no standard or internationally agreed upon guidelines, some key findings and features that demonstrate innovative ways that nurses can recommend and support patients with palliative care needs in the ED are known.

Models and Approaches

A report published in 2013 by the Improving Palliative Care-Emergency Medicine (IPAL-EM) initiative described 11 clinical demonstrations of ED palliative care integration, focusing on ED-initiated palliative care consultations.[15] The report identified that palliative care integration is on a spectrum ranging from traditional consultation to basic integration, advanced integration, and ED-focused advanced care. The practical delivery within this spectrum ranges from contacting the palliative care team in specific, individual situations, to fully integrated care with ED-owned responsibility for palliative care delivery. In the latter case, there may still be a relationship with the palliative care team, but features can include dual-certified ED practitioners, provision of individual case management for high-risk palliative care patients, palliative care training and education from the palliative care team, specific palliative care processes and procedures integrated into routine care, and an IDT approach.[15] Drawing from this report, ED nurses can review their own ED and hospital setting to identify local resources to improve quality of care. Examples of practice that can be adapted include working with in-hospital palliative care and specialty medical teams, developing or improving access to palliative care training programs, and collaboration with ED and community-based members of the IDT to create tailored processes for high-need patients.[15]

Encouraging emerging research is beginning to evaluate the impact of these different mechanisms. On the lower end of the spectrum (traditional consultation), there was one randomized clinical trial that compared QOL, depression, healthcare utilization, and survival in ED patients with advanced cancer between those randomized to ED-initiated palliative care consultation or to care as usual.[45] Results were statistically significant for QOL, with longer survival rates for those seen by the palliative care team.[45] An example of ED-focused care was conducted in Taiwan.[14] Led by a hospice and palliative medicine specialist, ED nurses and doctors received palliative care training, and residents rotated on hospice wards. Their program included education programs, monthly interdisciplinary meetings with the palliative care team, use of an app to communicate information and experiences, and identifying a specific emergency hospice room for dying patients. The study reports that initiation of do-not-resuscitate orders (DNRs) increased, as did palliative care consultation and ED nurse knowledge, timing, and method of consultation with the palliative care team.[14]

Where ED-focused advanced mechanisms are not possible, ED nurses can make use of different palliative care needs assessment tools to support their practice and improve quality of care. A systematic review of currently available tools, triggers, and criteria for palliative care ED patient assessment found a range of approaches. Nurses can find assessment tools for different patient populations, such as cancer, dementia, and older people.[5] Some draw on the expertise of different members of the IDT, such as social workers, nurses, and physicians.[5] Others can be applied at different points in the process of ED care, for example at triage, for palliative care consultation while in the ED, to trigger a palliative care evaluation while in the hospital, or to assess for the need for community or hospice services.[5] EDs should identify which tools most suit their patient populations and care processes and draw on the different members of the IDT, including social workers and case managers, to help implement high-quality care. The third and final part of the case study demonstrates in practical terms how such integration can take place.

Case Study: A Patient in the ED–Part 3

The RN returned to the husband and wife, who were sitting again, holding hands. MB had been weaned to a 3 L nasal cannula, on which her SaO_2 was stable at 89%, normal for her COPD. Her work of breathing had decreased, her anxiety had subsided, but she had a sharp pain in her right side from the chest tube placement, and her lower back was in spasm. The RN knew that, despite the pushback regarding the palliative care consult, she could still provide palliative care in the ED. She asked MB, “What is your main goal right now?” MB replied, “Right now I just want to have less pain, and to stay calm with my husband by my side.” The RN asked what she could do to alleviate some of the pain and anxiety, offering hot packs, a cool beverage, and a light massage, all of which MB accepted. The RN asked, “Is there anything you want to make sure does not happen tonight?” MB replied, “I don’t want another tube in my chest, or anywhere else for that matter.” The RN noted this in the patient’s chart and provided education to MB and her husband regarding ADs. With some time left before traveling to the floor, the RN asked MB about her passion for photography and about what prevented her from continuing to take photographs. MB cited her arthritis as the primary deterrent. The RN educated the patient regarding medication adherence and the benefit of a warm compress in the morning for osteoarthritis. Their conversation was interrupted by the transport team, who were there to take MB to the medical inpatient unit. The RN was able to identify a different doctor in the ED who had ordered palliative care consults in the past, and, after the RN shared the information about MB, the ED physician agreed with the nurse’s assessment and paged the palliative care team to ask if they could see her as soon as possible.

Discussion Points

Facilitators to palliative care:

- This RN has shown determination, enacting fundamental principles of palliative care in her care of MB despite resistance from her team. She asks the patient about what interventions she does *not* want during this hospital stay, an important step toward creating her AD and code status.
- The RN engages the patient on a personal level, offering complementary methods of symptom management and investigating what is important to the patient in her life. Education is provided where necessary.
- The RN identifies a provider who is “palliative friendly” and successfully ensures MB will receive a palliative care consult during her inpatient admission.

Ways to integrate palliative care:

- ED practitioners do not need to be palliative care specialists to offer palliative care. Finding out what matters to the patient, taking seriously those priorities even when they conflict with those of the ED, and offering creative solutions to address those needs can be done in any encounter with a patient. Standardized education for all ED practitioners can encourage these smaller scale incorporations of palliative care.
- Identifying allies, and therefore building support from within the ED team, will be crucial to creating lasting change within the ED setting.

Current Gaps and Next Steps

Despite increasing attention on the role of palliative care in the ED, further steps will be critical to meeting the demands of an aging population with extensive palliative care needs. High-quality research into the costs and comparative effectiveness of implementing palliative care in the ED setting may influence stakeholders to ensure that adequate palliative care consultation services exist. Moreover, while education is lacking for RNs, APRNs, PAs, and MDs alike,[46] there is minimal evidence of multidisciplinary approaches with tailored ED palliative care training, education, and certification.[14] It is recommend that EDs implement a systematized training on the basics of palliative care, as well as a standardized protocol for involving palliative care specialists in patient care. Education will reduce confusion over definitions and roles in palliative care, while increased access to palliative care professionals, including bereavement support services, social work, and homecare services, could eliminate much of the gap between the patients' and the providers' goals.[16] Finally, no palliative care program in an ED will be entirely successful unless the total hospital system also values palliative care. Of particular importance is the negative impact of delaying or avoiding advance care planning on the quality of a person's final months of life.[47] A greater ubiquity of ADs may increase the presence of patient-centered and palliative care delivery in the ED. Being at the front line of direct patient care, nurses are optimal resources for education and advance care planning discussions.

Conclusion

Palliative care in the ED has traditionally been highly challenging for multiple reasons, including the environment and "identity" of the ED and its staff and misunderstandings of palliative care among clinicians and patients. Despite this, growing numbers of palliative care patients are seen in the ED, reflecting a shift in the aging population. While there are numerous challenges, new models of care are emerging and showing good outcomes. ED palliative care will need to continue to evolve as the patient population changes. The nurse needs to be at the forefront and adaptable to such changes in order to best support patients and their families.

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CHAPTER 54

The Role of Nursing in Caring for Patients Receiving Palliative Surgery or Chemotherapy

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Key Points

- Patients and their families facing surgery or chemotherapy for advanced disease are often caught between the dichotomy of continuing aggressive treatment and the focus on quality supportive and palliative care.
- Palliative surgery and chemotherapy affect the physical, psychological, social, and spiritual well-being of both patients and families and impact healthcare system-related outcomes.
- Patients and families require support as they make decisions regarding the benefits and burdens of treatments for advanced disease.
- Nurses can help alleviate suffering by supporting patients and families through changes in treatment intent, the decision-making process, and supportive care needs during palliative surgery or chemotherapy.

Introduction

For patients with advanced cancer, treatment options are often limited. It is usually at this stage of the cancer continuum that discussion of palliative modalities of treatment occurs. These palliative modalities often include—but are not limited to—radiation, surgery, and chemotherapy. Patients with advanced cancer are often caught between the dichotomy of continuing aggressive treatment and the focus on quality supportive and palliative care.[1] Faced with these difficult decisions, patients and families become especially vulnerable and may experience heightened physical, psychological, social, and spiritual distress.[2] This chapter describes the use of surgery and chemotherapy/cancer investigational agents as a palliative treatment for patients with advanced cancer.

Palliative Surgery

Palliative surgery is defined as any surgical interventions in patients with incurable malignancy; the treatment intent is focused on symptom management and quality of life (QOL).[3,4] Data from the current literature suggest that approximately 21% of surgical procedures are performed with a palliative intent,[5] while 40% of inpatient surgical consultations meet the criteria for palliative evaluation.[5–7] A relatively novel approach in oncology care, the field of palliative surgery is rapidly increasing and becoming recognized as a key component of comprehensive cancer care.

Decision-Making and Goals of Care in Palliative Surgery

Figure 54.1 depicts the treatment decision-making process in palliative surgery; it is derived from research conducted at the City of Hope Medical Center. The decision-making process in palliative surgery involves perspectives from the patient, the family, and the healthcare team and impacts all dimensions of QOL. Patients and families must weigh the potential benefits and harms of the surgery proposed, whereas the healthcare team considers factors such as the difficulty of the procedure, the duration of hospitalization, recovery time, and anticipated disease progression.[8,9] For patients contemplating palliative surgery, the primary decision-making factor is focused on the physical impact of uncontrolled symptoms.[10] Patients often perceive surgery as their best option, even though surgical risks are inherent and may influence decision-making.[11] Other factors for decision-making include the social impact of symptoms, preservation of normal functions (i.e., the desire to eat and drink), prolonged life expectancy, and maintenance of hope.[12–14] Common reasons for declining surgery include complication concerns, physician recommendations, and religious issues.[14]

Family caregivers typically participate in the decision-making process, and they also experience significant disruptions in QOL preoperatively.[15,16] Psychological issues were most pronounced, and common concerns included uncertainty, fears regarding the future, and loss.[15] Surgeons experience challenges in maintaining patients' health while trying to communicate an honest assessment of their prognosis.[12]

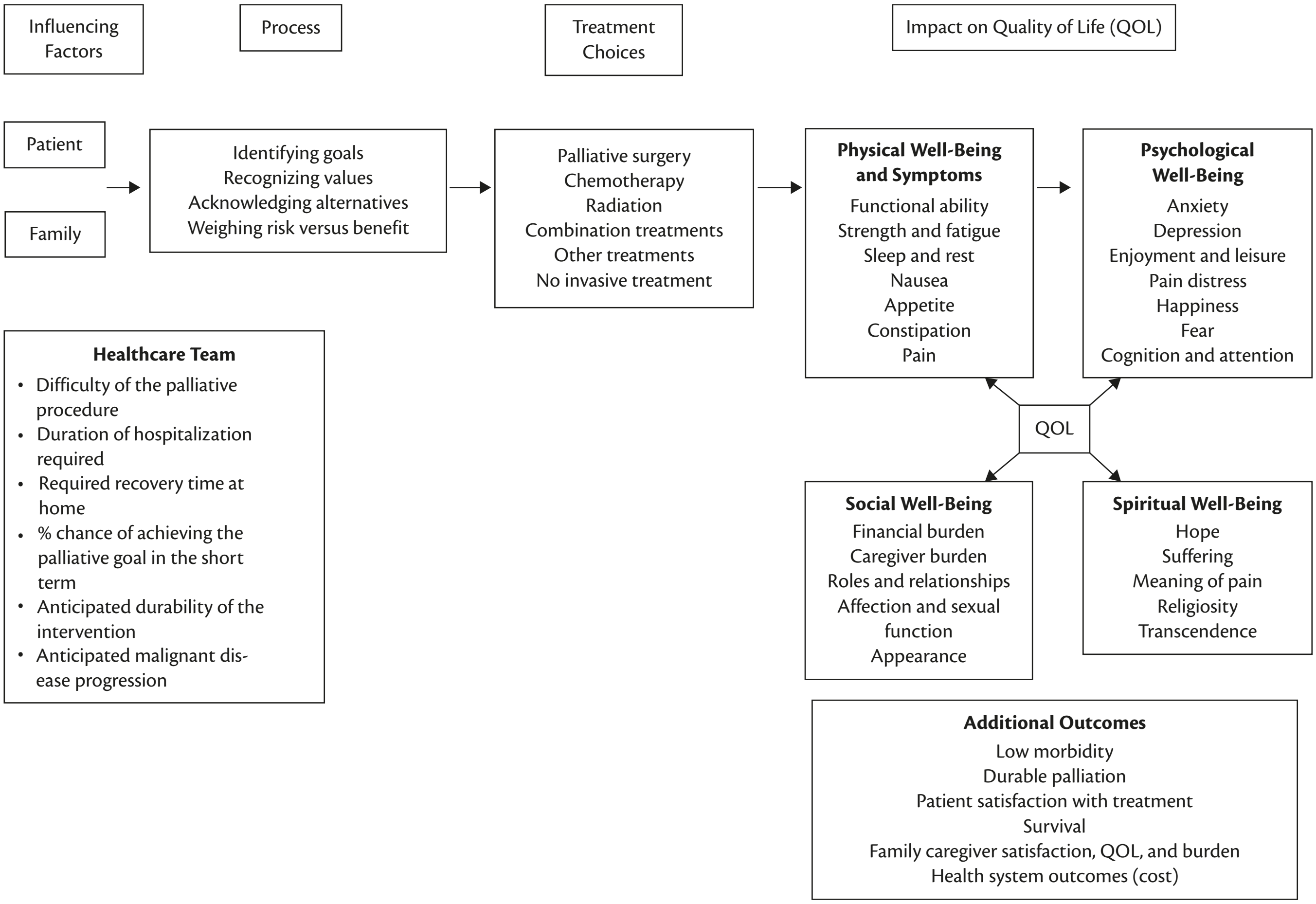
Influencing Factors
Process
Treatment Choices
Impact on Quality of Life (QOL)
Patient
Family
Identifying goals
Recognizing values
Acknowledging alternatives
Weighing risk versus benefit
Palliative surgery
Chemotherapy
Radiation
Combination treatments
Other treatments
No invasive treatment
Physical Well-Being and Symptoms
Functional ability
Strength and fatigue
Sleep and rest
Nausea
Appetite
Constipation
Pain
Psychological Well-Being
Anxiety
Depression
Enjoyment and leisure
Pain distress
Happiness
Fear
Cognition and attention
Healthcare Team
Difficulty of the palliative procedure
Duration of hospitalization required
Required recovery time at home
% chance of achieving the palliative goal in the short term
Anticipated durability of the intervention
Anticipated malignant disease progression
QOL
Social Well-Being
Financial burden
Caregiver burden
Roles and relationships
Affection and sexual function
Appearance
Spiritual Well-Being
Hope
Suffering
Meaning of pain
Religiosity
Transcendence
Additional Outcomes
Low morbidity
Durable palliation
Patient satisfaction with treatment
Survival
Family caregiver satisfaction, QOL, and burden
Health system outcomes (cost)

Figure 54.1 Treatment decision-making in palliative surgery.
Source: References 6, 7, 10, 12, 15.

Examples of Common Indications for Surgical Palliation

Table 54.1 presents a list of common indications for surgical palliation. Malignant bowel obstructions (MBO) are a common complication associated with advanced cancer usually of gastrointestinal or gynecological origin. MBO is defined as luminal narrowing of small or large bowel with clinical evidence of bowel obstruction in the setting of metastatic intraabdominal cancer; the obstruction can be either partial or complete. Colorectal and ovarian cancers are the most common intraabdominal cancers associated with MBO, whereas breast cancer and melanoma are the most common extraabdominal causes. It is a common complication associated with metastatic disease and/or peritoneal carcinomatosis. Patients will often present with one or more of the following symptoms: nausea, vomiting, abdominal pain, obstipation, diarrhea (a result of bacterial overgrowth secondary to blockage of fecal material), distended abdomen, and fevers. MBO can be either partial or complete. Patients with MBO will often have shorter prognoses and have a diminished QOL, with a median survival of 95 days.[17]

Table 54.1 Common indications for surgical palliation

Indications	Symptoms to palliate
Malignant bowel obstruction	Nausea and vomiting Pain
Gastric outlet obstruction	Nausea and vomiting Early satiety
Biliary obstruction	Pruritus Liver failure
Malignant ascites	Dyspnea Pain
Malignant pleural effusions	Dyspnea

The pathophysiology of bowel obstruction is related to mechanical obstruction (extrinsic or intrinsic occlusion by tumor) or functional obstruction/adynamic ileus (caused by tumor infiltrating the bowel wall, nerves, and plexus). MBO can be classified by partial versus total obstruction and proximal versus distal bowel obstruction. The algorithm of care for a proximal versus distal bowel obstruction varies. Patients with gastric or proximal small-bowel obstruction may present with bilious vomiting; postprandial periumbilical, intermittent abdominal pain; and intolerance to oral intake, but no abdominal distention. Malignant small-bowel obstructions often occur at the level of the duodenum, as a result of extrinsic compression or direct invasion by the tumor. Pancreatic adenocarcinoma, cholangiocarcinoma, and gallbladder carcinoma are the most common tumors to cause duodenal obstruction. In contrast, distal small-bowel or large-bowel obstruction may present with malodorous emesis; localized deep, visceral pain, occurring at longer intervals; and abdominal distention.[17,18]

Obtaining a thorough subjective/objective history and assessment from the patient coupled with a complete physical exam are key elements in the optimal diagnosis and care of a patient with MBO. Although the diagnosis of MBO can often be established based on history and physical exam, obstruction is confirmed with imaging studies and begins with an abdominal x-ray followed by a computed tomography (CT) scan. Once an obstruction site is identified, direct visualization by endoscopy by a gastroenterologist may aid in the evaluation and care for a patient with MBO. The abdominal x-ray is used to look for dilated loops of bowel, air–fluid levels, or both. The abdominal CT is useful in making the diagnosis of bowel obstruction, evaluating for complications, and staging and choosing surgical or endoscopic intervention. An abdominal CT has a sensitivity of 93%, a specificity of 100%, and an accuracy of 94% in determining the cause of bowel obstruction.

Initial assessment of the patient includes determination of whether an acute abdominal emergency requires surgical intervention. Surgical treatment options for MBO include debulking, diverting colostomy, intestinal bypass, and resection. In general, surgical candidacy is based on performance status, the extent of malignancy, and prognosis. Resection should be considered in patients with good performance status and localized disease.[19] In advanced cancer, the benefit of surgical intervention is less clear and is incumbent on patients' comorbidities and prognosis. Poor prognostic indicators include age greater than 63 years, malnutrition, low albumin levels, ascites/peritoneal carcinomatosis, metastatic effusions, multiple sites of obstruction, prior radiation to abdomen, prolonged bowel passage time, and short diagnosis to obstruction time. Perioperative mortality ranges from 20% to 40%, with complication rates as high as 90% in advanced cancer patients.

Nasogastric tubes are often initially placed for decompression but are temporary (although terminal cancer patients placed on hospice care have also kept these in place, but these situations are rare and exceptional). Nasogastric tubes are very uncomfortable, and are not a long-term treatment option as they can negatively impact a patient's QOL. Nonsurgical patients with chronic or recurrent obstructions who respond symptomatically from nasogastric tube decompression and have ongoing high gastric output are often considered for a venting percutaneous gastrostomy (G) tube for palliative purposes. While symptomatic relief with a G tube may be achieved in 83–93% of patients, there is insufficient evidence to show that tube placement improves nutritional status or QOL. G tubes are usually avoided in patients with portal hypertension, large-volume ascites, and high bleeding risk.

Placement of self-expanding metallic stents (SEMS) offers palliation to nonsurgical candidates with a single point of obstruction at the gastric outlet or proximal small bowel. These stents can be placed endoscopically by gastroenterologists or by interventional radiologists. SEMS may be a good option for patients with a single site of proximal obstruction and intermediate life expectancy. Successful palliation of symptoms with duodenal stent placement has been reported to be as high as 90%. Covered SEMS have been shown to maintain patency longer but are not available in the United States. Complications include perforation (1.2%), stent migration (5%), and stent obstruction (18%). There are limited data comparing stenting to surgical bypass.[20,21]

Metal stents placed for malignant colorectal obstruction also have a high palliative success rate, with improvement in symptoms in about 75% of patients. Complications are similar to those with upper gastrointestinal obstruction stenting and include perforation (4.5%), stent migration (11%), and reobstruction (12%). Technical success is less likely with proximal colonic obstruction than distal obstruction, and with obstructions related to extrinsic compression than intraluminal obstruction.

MBO is a negative indicator of a patient's prognosis, with an average survival rate of 3–8 months in patients who undergo surgery and 4–5 weeks in inoperable cases. Because most patients with MBO are not surgical candidates, medical therapy and palliation (i.e., supportive care) of symptoms is the common management for these patients. Spontaneous resolution of obstruction in an inoperable patient with MBO utilizing nasogastric decompression and medical therapy has been reported to occur in 30% of patients. Intravenous hydration and electrolyte repletion are critical in the acute stages of management. A multifaceted approach to symptom management includes the use of parenteral opioids, antiemetics, antispasmodics, and antisecretory agents, and hospitalization is common.

Opioids can be administered via intravenous, subcutaneous, or transdermal routes to prevent exacerbating nausea. Antiemetics are often a staple in MBO treatment. Combination medical therapy with different mechanisms is more effective. While metoclopramide is favored over other antiemetics in patients with functional obstruction, it should be avoided in complete bowel obstruction or if it seems to worsen abdominal pain or nausea. Other antiemetics that can be used are neuroleptics (haloperidol, prochlorperazine, chlorpromazine) and/or antihistaminic drugs. Antagonists of the 5-HT3 receptors (ondansetron or granisetron) are another option, though they may have more of a constipating effect than the other drug classes.

Anticholinergic agents such as scopolamine and glycopyrrolate can alleviate symptoms (by reducing gastrointestinal fluid secretions and cramping related to peristalsis), but side effects may be dose-limiting. Evidence supports the use of somatostatin analogues such as octreotide (Sandostatin) to decrease gastrointestinal secretions and increase water/electrolyte absorption. This medication is usually well tolerated. Antihistamines and proton-pump inhibitors can be used as adjunctive therapy as well. Corticosteroids are recommended for their bimodal benefit of relieving nausea and decreasing tumor-related inflammation and edema. Dexamethasone may even reduce bowel obstruction and lead to spontaneous resolution in MBO related to advanced gastrointestinal and ovarian cancers.[22]

MBO represents an advanced stage of cancer and can signal the transition toward palliative treatment for many patients. The decision to pursue medical versus surgical treatment depends on a patient's general health status and the extent of cancer spread. It is important for all nurses to be proactive and knowledgeable in identifying and managing symptoms with medications and coordinating the care with a multidisciplinary team. Initiation of discussions about goals of care, focused on nutrition and code status, is also appropriate and can guide transition of care decisions at discharge. The approach to treatment of MBO should be individualized to each patient.[23]

The following case study illustrates the treatment decision-making process for MBO and subsequent treatments for managing symptoms and QOL.

Case Study: A Patient with Malignant Bowel Obstruction

A 64-year-old Korean American man recently diagnosed with poorly differentiated gastric adenocarcinoma containing signet ring cell features on active chemotherapy was admitted with a 1-day history of severe left lower quadrant abdominal pain radiating throughout the abdomen, associated nausea, and 2 days without bowel movements or flatus. He had a low-grade temperature, was tachycardic, and on physical exam had an abdomen that was distended, tympanic, and markedly tender with faint bowel sounds. A complete blood count (CBC), basic metabolic panel, and liver function tests were unremarkable. An abdominal x-ray revealed multiple dilated loops of small bowel and a "string of pearls" appearance in the left mid-abdomen with multiple air–fluid levels at differing levels. A CT scan showed a moderate- to high-grade small-bowel obstruction with a transition point in the pelvis approximately 25 cm proximal to the ileocecal valve, with evidence of omental metastases.

The patient was subsequently admitted to the hospital and had a nasogastric tube inserted and was connected to low-intermittent wall suction. Intravenous fluids were initiated with pain medications and antiemetics were ordered. General surgery was consulted, but, due to extensive metastatic disease, including suspected peritoneal carcinomatosis on CT scan, the patient was felt to be a poor surgical candidate, and conservative management was continued. Total parenteral nutrition (TPN) was started, and dexamethasone/Octreotide was added.

The patient was subsequently evaluated by the gastroenterology team and underwent a percutaneous venting G tube placement for palliation of his abdominal obstruction. When pain and nausea had finally improved, he was transitioned to full liquid diet and maintained on total parenteral nutrition after discharge. He was discharged on oral metoclopramide and a course of dexamethasone.

Gastric outlet obstruction (GOO) is a consequence of advanced cancer that produces a mechanical impediment to gastric emptying. Patients present with intermittent symptoms that progress until obstruction is complete. Vomiting is the cardinal symptom. Initially, patients may demonstrate better tolerance to liquids than solid food. In advanced GOO, patients may develop significant weight loss and protein malnutrition. Malnutrition is a late sign. In the acute or chronic phase of obstruction, continuous vomiting may lead to dehydration and electrolyte abnormalities.[24,25]

Intrinsic or extrinsic obstruction of the pyloric channel or duodenum is the usual pathophysiology of GOO. When obstruction persists, patients may develop significant and progressive gastric dilatation. The stomach eventually loses its contractility. Undigested food accumulates and may represent a constant risk for aspiration pneumonia. The most common malignancy to cause GOO is primary gastric adenocarcinoma, followed by carcinoma of the pancreas and gallbladder, although it is also not uncommon to find presentations in patients with lobular breast cancer.

GOOs are either benign or malignant. As part of the initial workup, as in MBO, the patient must undergo a series of tests to differentiate between benign and malignant processes because definitive treatment is based on recognition of the specific underlying cause. These include baseline blood work, especially the electrolyte profile of a patient. Additionally, barium swallow studies and upper endoscopy are the main tests used to help make the diagnosis to help guide the management of patients diagnosed with GOO.

The treatment for GOO depends on the extent and cause and is usually managed surgically or medically. Both surgery and gastroenterology teams are often co-managing this patient population. GOO due to benign ulcer disease may be treated medically if results of imaging studies or endoscopy determine that acute inflammation and edema are the principal causes of the outlet obstruction (as opposed to scarring and fibrosis, which may be fixed).

Surgical management is considered when medical therapy fails. Contraindications for surgery relate to the extent of obstruction and the patient's medical condition as well as the extent of the cancer. Most patients benefit from an initial period of gastric decompression, hydration, and correction of electrolyte imbalances, TPN, or distal tube placement for feeding (e.g., placed via a percutaneous jejunostomy). Palliation via endoscopically placed stents are considered to improve QOL when terminal cancer is imminent and life expectancy may be limited to a few months. The underlying cause of GOO must be considered. Medications to combat symptoms including proton pump inhibitors (ulcer-related GOO), antiemetics, and pain medications are staples in caring for patients with GOO, in addition to an endoscopic or surgical intervention for palliation.[26]

Biliary obstructions occur when the bile ducts, the tubes that carry bile from the liver to the gallbladder and small intestine, become blocked. Bile is secreted in the liver and contains cholesterol, bile salts, and waste products such as bilirubin. They help to digest fats. Bile passes out of the liver through the bile ducts and is stored in the gallbladder. After a meal, it is released into the small intestine. Biliary obstructions can lead to obstructive jaundice due to an accumulation of bilirubin levels, and patients will often present with pruritus, bilateral scleral icterus, and yellowed discoloration of their skin. They may even note clay-colored stools and dark amber urine. The possible causes of a blocked bile duct include cysts of the common bile duct, enlarged lymph nodes in the porta hepatis, gallstones, inflammation of the bile ducts, narrowing of the bile ducts from scarring, gallbladder surgery injury, and bile duct or pancreatic cancers. Other gastrointestinal-related cancers with tumor spread to the biliary tree are also common. Infections and immunosuppression are also associated with biliary obstructions.[27]

Clinical diagnosis of biliary obstruction includes a complete CBC to rule out infection and a comprehensive panel including a liver function panel, prothrombin time, urine bilirubin, and amylase/lipase levels. Commonly used imaging to evaluate the patency and extent of a blocked bile duct include an abdominal ultrasound and CT scan, endoscopic retrograde cholangiopancreatography (ERCP), percutaneous transhepatic cholangiogram (PTCA), and magnetic resonance imaging (MRI).[27]

Patients with biliary obstruction are often a diagnostic and therapeutic challenge due to the site and complexity of biliary obstruction and wide differential diagnosis. Multidisciplinary decision-making is required after laboratory and imaging workup. The gastrointestinal team is an asset in caring for these patients, likely with advanced cancer. Endoscopic approaches to biliary drainage are preferred in most scenarios, and recent advances in therapeutic endoscopic ultrasound allow drainage where the previous alternatives were only percutaneous or surgical. The goal for treatment is to address the biliary obstruction. If left untreated, prognosis is very poor with short life expectancy. Long term, patients may develop worsening liver complications including hepatic encephalopathy and cirrhosis. A percutaneous transhepatic biliary drain is often used to help decompress the biliary tree, in addition to biliary stenting, as guided by the gastroenterology team. Infection-related biliary obstructions are not only palliated by an interventional/endoscopic approach but with supportive care measures to control symptoms and antimicrobials to combat infection.[28–30]

Ascites is defined as fluid accumulation within the peritoneal cavity. Although ascites can be seen in patients with cirrhosis and resulting portal hypertension (approximately 85% of cases), in 7–10% of patients with ascites the condition develops secondary to a malignancy. The most common malignancies associated with the development of ascites include colon/rectum, ovary, breast, lung, pancreatic, and liver cancers, as well as lymphoma. About half of patients with malignant ascites have peritoneal carcinomatosis, with an additional 13% of patients having extensive liver metastases resulting in portal hypertension. Ascites is a common manifestation in patients with advanced cancer. The most common cancers associated with ascites are adenocarcinomas of the ovary, breast, colon, stomach, and pancreas.[31]

Malignant ascites can develop through several mechanisms: blocked lymphatic channels as a result of malignancy, direct production of fluid into the peritoneal cavity by advanced malignancy, and when "functional" cirrhosis develops in patients with extensive liver metastases resulting in portal hypertension. The development of malignant ascites carries a grave prognostic sign, with the median survival reported anywhere between 1 and 4 months.

Cancer patients with malignant ascites manifest symptoms similar to noncancer patients with ascites secondary to cirrhosis. Clinically, one may visualize spider angiomas, distended umbilical veins (caput medusa), sclera icterus, jaundice, anasarca, and a distended abdomen. They may have increased dullness to percussion or shifting dullness. Patients can complain of increasing abdominal girth, generalized abdominal pain, and shortness of breath from fluid overload.

Depending on the clinical presentation and expected survival, a diagnostic evaluation is usually indicated because it will impact both prognosis and the treatment approach. Key tests include serum albumin and protein and a simultaneous diagnostic paracentesis checking ascitic fluid, white blood cell (WBC) counts, albumin, protein, and cytology. An abdominal ultrasound can be performed to confirm the presence of ascites within the abdomen. Upon verification of ascites, patients can undergo paracentesis in order to remove ascitic fluid for analysis. If the ascitic fluid is characterized by malignant cancer cells, the patient is diagnosed with malignant ascites.[32]

Management of patients with ascites in gastrointestinal malignancies will vary. There are different approaches to the treatment of malignant ascites, ranging from symptomatic relief with simple drainage procedures such as paracentesis to chemotherapy and debulking surgery aimed at treating the underlying cancer. Medical management is often used, including diuretics, beta blockers, and anti-hypertensive medications to reduce fluid accumulation related to portal hypertension. Malignant ascites impacts QOL and can be improved with these interventions. Optimizing nutritional intake and protein is important. If ascites continues to progress despite drainage procedures, appropriate patient candidates can undergo interventional radiology-guided procedures such as a tunneled abdominal catheter, peritoneal shunts, and pigtail drains, which allow for patients to drain the abdominal fluid on an as-needed basis. While this modality runs a potential risk of infection or leakage, it allows patients to drain in the comfort of their own homes, or drains may even be placed to optimize supportive care measures in patients transitioned to hospice care. A multidisciplinary approach is needed to care for these types of patients because their care requires input from the oncology/hematology team, the nursing staff, interventional radiology, a dietary team, and a hospice team, if appropriate.[33,34]

In advanced stages, malignancies are frequently complicated by *malignant pleural effusions* (MPE) that can present along with or as a recurrence of primary malignancies. MPE is a condition whereby fluid accumulates within the pleural space. This is caused by direct pleural invasion by tumor cells, which results in increased permeability of the pleural micro-vessels, a disturbance of the normal Starling forces regulating reabsorption of fluid in the pleural space, and involvement of local and mediastinal lymph nodes causing reduced fluid reabsorption of the parietal pleura.[35] The increased fluid accumulating within the pleural space prevents full expansion of the lung, preventing it from approximating to the chest wall. The mere presence of a MPE implies disseminated or advanced disease and reduced survival. Left untreated, a symptomatic effusion impacts significantly on performance status and QOL. The symptoms associated with MPE can be disabling and distressing, leading to dyspnea, pain, cough, discomfort, emotional distress, anxiety, chest heaviness, and fatigue, with dyspnea being the most common presenting symptom, occurring in more than half of the cases.[36] Because MPE causes distress and disability and is associated with brief survival, initial management has chiefly been palliative with either drainage of fluid serially over time or obliteration of the pleural space by pleurodesis. The ideal goals of treatment for this patient population, given the poor prognosis and short life expectancy, include symptom relief or, better yet, symptom avoidance; restoration of near normal activity; palliation of symptoms with reduction of adverse effects; decreasing complications (trapped or loculated lung); decreasing cost of care by minimizing urgent care or emergency room visits or hospital admissions; improvement in performance status; improvement in QOL; and potentially increased survival.

Generally, there are a variety of methods available for palliative treatment of MPE, and there is little compelling evidence to guide clinicians in the choice of the best methods. Thoracentesis is the first step in management in almost all cases of MPE to confirm histology and also to determine the need for a more definitive intervention. Utilizing intermittent thoracentesis can be an option for treatment and provides an opportunity for periodic symptom relief on an as-needed basis; and it may be the best option for patients with a short anticipated survival time. Pleurodesis aims to produce adhesions of the pleura by chemical or surgical means in order to obliterate the pleural space and, by doing so, prevent fluid recurrence. Multiple physical techniques have been used to produce adhesions between the parietal and visceral pleura, obliterate the space, and prevent recurrence. They include open or thoracoscopic pleurectomy, gauze abrasion, or laser pleurodesis. Surgical decortication is an option not routinely utilized as this potentially dangerous procedure may result in severe complications such as bronchopleural fistula and empyema. In carefully selected cases with early multiloculated malignant pleural effusion, gentle thoracoscopic debridement can restore a single lung cavity and allow effective pleural drainage or pleurodesis. Surgical methods have not been demonstrated to have any advantage over simpler chemical pleurodesis techniques in the treatment of malignant effusions. Chemical agents utilized for pleurodesis include antibiotics such as tetracycline, doxycycline, minocycline, erythromycin, and bleomycin or utilizing a talc aerosol or slurry.[37]

An indwelling pleural catheter (IPC) involves the insertion of a tunneled, small-bore, cuffed, silicone catheter into the pleural cavity. IPC placement is aimed to optimize emptying of the pleural space by intermittently draining the effusion in order to preserve adequate lung expansion. The site for the insertion is identified with thoracic ultrasonography. The guide wire is inserted at the thoracic inlet area, then the pleural catheter is tunneled under the soft tissue of the chest wall to the guide wire area for insertion into the pleural space.[38] The procedure can be performed at the bedside under sterile conditions or on an outpatient basis under local anesthesia. This is followed by home drainage performed by a home care provider or trained family members.

Palliative Chemotherapy

Palliative chemotherapy, in its broadest sense, is the use of systemic antineoplastic agents in noncurative settings to optimize symptom control and maintain QOL.[39] The literature clearly supports the role of chemotherapy in managing troublesome symptoms and maintaining QOL[39] in advanced pancreatic cancer, non–small cell lung cancer, and breast cancer. This is in contrast to "end-of-life" chemotherapy, which is prescribed and given close to death (within 7–14 days of death). Here, chemotherapy does not improve survival and may likely worsen symptoms and QOL.

Trends in the aggressiveness of cancer care at the end of life have been explored in the literature. Indicators of aggressive care include intensive use of chemotherapy, low rates of hospice use, emergency room visits, hospitalization, and intensive care unit (ICU) admissions.[40] Rates of palliative chemotherapy use continue to rise in older adults on Medicare and are estimated to be close to 30%.[41] For patients who received palliative chemotherapy, 15.7% received treatments up to 2 weeks before death.[41] Most palliative chemotherapy treatments are initiated within 30 days of death.[42] An increasing proportion of patients used hospice services, but the services were primarily initiated within the last 3 days of life.[43] The elderly, female, nonwhite, and unmarried patients were less likely to receive aggressive care.[42,44–46]

Decision-Making and Goals of Care in Palliative Chemotherapy

Similar to palliative surgery, the primary goal of palliative chemotherapy in advanced disease is to control symptoms and maintain QOL. Prognostic factors have been used to guide treatment decision-making in palliative chemotherapy. One of the most important prognostic factors is performance status.[47–49] A severely debilitated patient with a restricted performance status is more likely to sustain excessive chemotherapy toxicity. The decision to treat or not to treat is based not only on prognostic indicators but also on the patient's perspective. Chemotherapy involves a commitment on the part of the patient and family to travel to the treating institution on a scheduled basis.[50] Repeated hospitalizations, venipunctures, cannulations, investigations, and assessments over and beyond the actual administration of chemotherapy are inevitable routines of cancer treatment. Aside from assessing antitumor effects and the toxicity of chemotherapy, the overall positive or negative impact of the treatment on QOL must also be addressed.[51] These factors need to be addressed with patients and families in an effort to facilitate the decision-making process.

Clear communication between providers, patients, and families is a critical component of the treatment decision-making process in palliative chemotherapy. The current evidence suggests that patients with advanced, incurable cancers are often unclear about the survival gain of palliative chemotherapy.[1] Patients and families with advanced cancer may perceive more benefits from cancer treatments in general. They are often more likely to accept intensive treatment with debilitating toxicities in exchange for a small probability of cure, prolongation of life, and symptom relief.[2,52,53] Patients may choose chemotherapy for a likely survival benefit of 3 months only if the treatment positively affected QOL as well.[52,54] Conflicts between patients' preferences and the actual care they received greatly affected their decision-making.[2]

When curative intent of treatment becomes impossible, practitioners should begin to address the intent to treat as palliation of disease-related symptoms. This initial communication is traditionally the domain of the treating physician. However, with increasingly more collaborative practices emerging among nurses, advanced practice registered nurses (ARPNs), and physicians, an interdisciplinary approach offers the best support for patients and families during this difficult and vulnerable time.[39,47] Communication of difficult news should best be conducted in a prearranged consultation session in which the treating physician, nurse, and social worker together deliver the information to the patient, the family, and other individuals who are integral to the decision-making process. Nurses can foster this interdisciplinary approach of delivering difficult news through collaboration and communication with experts across disciplines. Nurses are often the first to recognize the need for dialogue between the healthcare team and the patient and family regarding treatment intent and prognosis.[53–55] Therefore, nurses can advocate for patients by recommending and organizing these important communication sessions to alleviate unnecessary suffering for patients and families.

When discussing the possibility of palliative chemotherapy as a treatment choice, it is essential to learn about other specific factors that may affect the decision-making process. Nurses can facilitate and perform the assessment to obtain this vital information. This assessment may include (1) questions and decisions that need to be addressed in the patient's or family's lives and (2) a special upcoming event or specific unfinished business that must be completed.[4] Recent studies of concurrent palliative care with standard oncologic care have demonstrated that advanced cancer patients treated with palliative chemotherapy had improved health-related QOL, reduction in symptom burden, and potential to reduce use of aggressive treatment at end of life[56] while having improvement in survival.[57] Therefore, patients should have access to palliative care early in the decision-making process and throughout the treatment course.[58]

Case Study: A Patient with Lung Cancer

Mr. L is a 73-year-old man with a 40-pack-year history of smoking who was diagnosed with metastatic non–small cell lung cancer. At the time of diagnosis, he had widespread disease to his bones. Because of the bone metastasis, Mr. L had been experiencing escalating pain. He spent most of his days at home and in bed due to the escalating pain as well as cancer-related fatigue. Mr. L was recently started on immunotherapy through a clinical trial. He had decided to continue with treatment because of his grandchildren. After approximately 4 months of treatment, Mr. L's condition deteriorated, with worsening shortness of breath, increasing fatigue, and worsening of pain. He was finally transferred to an inpatient hospice facility, and he died 3 days following admission.

In this case, a focus on watchful waiting or aggressive supportive care was indicated. Mr. L's performance status was gradually declining; therefore, he could be anticipated to experience more difficulties with treatment side effects. The immunotherapy did not have a long-term effect on Mr. L's pain. Aggressive supportive care involving experts such as pain specialists would have been beneficial for symptom management and QOL for this patient immediately following diagnosis. Another important aspect of caring for Mr. L was to support his family. Because Mr. L's decision to continue with treatments was for his grandchildren, supportive care experts who specialize in working with young families or children could have been included to aid Mr. L in treatment decision-making.

Clinical Trial Participation and Advanced Cancer

Patients with advanced cancer are frequently offered the opportunity to enroll in a phase I clinical trial. It is important to note that phase I studies are designed to determine the toxicity and maximum tolerated dose of potential treatments, mostly for currently incurable cancers. These studies are not designed to have, and do not have the intended purpose of a therapeutic effect. In fact, studies have shown that therapeutic effects from cancer investigational therapeutic agents occur in only 2–4% of subjects enrolled in a phase I clinical trial.[47,59] Patient expectations for participation in clinical trials include a response to therapy, a reduction in symptoms, and improved and increased communication with their physicians.[60–67]

The current evidence suggests that there is controversy about whether patients with advanced incurable cancers, when faced with decision-making regarding their plan of care, fully understand the choices that are available to them. Studies have found that patients are aware of other alternatives at the end of life, but their overwhelming need to fight their cancer at any cost prevents them from seriously considering the other alternatives.[68–70] Patients who would qualify for hospice services as regulated by Medicare often have very little understanding of admission criteria and services rendered. The impact of clinical trial participation on physical symptoms related to advanced cancer is complex, and there is a paucity of data regarding the extent of these symptoms.[71] Although the structure and requirement of a clinical trial protocol mandates the inclusion of a plan of action for unexpected physical symptoms, these plans often are focused on pharmacological interventions only. For example, if nausea and/or vomiting is an anticipated or expected side effect, a protocol of which antiemetic agents to use is written into the clinical trial protocol itself. However, the psychological and social distress from this side effect is not included in the plan. A clinical trial protocol generally does not include plans that specifically state the need for referrals to other allied health professionals, such as palliative care specialists and psychologists.[71]

The psychological and cognitive symptoms of patients participating in research studies vary. Some patients may be distressed to be told that they are not eligible for inclusion into clinical trials. Research subjects may also have difficulty when an experimental treatment fails, which often mandates the withdrawal of subjects from the treatment protocol. One potential advantage of enrollment in clinical trials is that several members of the research team care for these patients. There are regularly scheduled visits, and that attention may affect the patient's psychological well-being. This added attention might lead to early detection of psychological symptoms that are indicative of depression, sadness, anxiety, or irritability.[71–73] Subtle changes in psychological effects might be readily detected by research personnel, and nurses are an integral part of this team. However, for this added attention to be beneficial to patients and families, it is important for research teams to work collaboratively with allied health professionals and palliative care specialists to address concerns in all areas of patient and family well-being.

Economic demands and caregiving needs may also be affected by clinical trial participation.[73] Financial burdens may be increased for clinical trial participants even if the experimental agents are provided free of charge. The usual intensive monitoring and testing that can sharply increase with participation in clinical trials may not be covered by either the trial budget itself or the patient's insurance. The frequent visits for treatment, physician assessment, and various other procedures that are often mandated in clinical trial protocols may incur further economic burdens in terms of expenses for travel and room and board.[73]

The needs of caregivers and families may also change with clinical trial participation. Families experience tremendous physical, psychological, social, and spiritual concerns that are related to the patient's well-being. Physical symptoms such as fatigue can plague caregivers and families who are faced with the complex care of patients with advanced cancer.[50,58] The complexity of navigating through the healthcare and insurance systems can place tremendous burdens on both patients and caregivers. Social exposure may be diminished for caregivers because much of their days are spent caring for their loved ones.[15,51,61] Finally, the agony of being a witness to a loved one's suffering and the prospect of grief and bereavement in terminal illness may present caregivers with spiritual and existential distress.

Attending to the spiritual and existential needs of patients with advanced cancer is an important factor in the overall experience of patients and families facing the inevitability of terminal illness. It is often at this point in the cancer trajectory that patients experience the needs of altruism.[66,74] Patients and families who recognize the diminishing hope of survival may find comfort and solace in the possibility of contributing to the advancement of science through participation in clinical trials.[62] Others may choose to focus on using precious time to concentrate on more personal goals, such as unfinished business and QOL.

The Role of Nurses in Palliative Surgery and Chemotherapy

The care of patients undergoing palliative surgery is often focused more on the medical aspects, yet nursing care is essential throughout all phases of preoperative, intraoperative, immediate postoperative, and postoperative recovery and discharge. This is a critical time, with numerous transitions between care settings, and nurses play a vital role in ensuring continuity across settings such as the operating room, ICU, postoperative surgical unit, and home care. A prime example is the role of nursing in ensuring pain management by assessing a patient's chronic pain problem at the time of admission to plan adequate analgesia as the patient is admitted for surgery. The nurse then collaborates with the physician and pharmacist to plan the analgesic orders for the transition from the oral analgesics used preoperatively to an appropriate regimen postoperatively. Additional monitoring is needed as the patient's pain may escalate after major surgery. The nurse should also ensure that the appropriate changes are instituted as the patient goes from chronic oral medications taken at home to parenteral administration required in the postoperative period and in the ICU. Maintaining adequate analgesia after discharge from the ICU to the postoperative unit and then to home care is essential for the patient's timely discharge to home and remains a requirement during recovery. This is a simple example of just one aspect of care in pain management, illustrating the vital role of nursing during this very acute phase of treatment.

Oncology nurses have many different roles in the conduct of cancer clinical trials. First and foremost, the process of obtaining true informed consent is a critical factor, not only in improving patient accrual into clinical trials but also in the overall well-being of patients and their families. The informed consent process is an opportunity to provide accurate information regarding important factors that affect the patient's and family's decision-making process in advanced cancer. These factors include trial procedures and potential risks and benefits.[65] The initial informed consent process is also a time to correct any misconceptions and allay unfounded fears and to provide sufficient time for patients and families to thoughtfully consider clinical trial participation.[74] A pre-decisional support process provided by oncology nurses may influence the soundness of patients' decisions to enroll in clinical trials.[70] Nursing interventions that would assist in well-considered decisions include helping patients gather additional relevant sources of information, describing patients' roles and rights in studies, encouraging patients to define their own reasons for participating in clinical trials, and supporting patients in making decisions that correspond with their personal values and wishes.[75,76] APRNs, such as clinical nurse specialists and nurse practitioners, can be important factors in the conduct of clinical trials. Expertise in symptom management and clinical problem-solving is a key asset for APRNs in the research setting. For example, nurse practitioners working in a clinical trial setting have an expanded scope of practice that allows them to perform routine follow-up physical examinations as well as diagnose and manage treatment complications. This level of participation in patient and family care may enhance patient satisfaction, compliance, and retention.

Nurses will often encounter end-of-life situations. During these difficult times, patients and their loved ones will desire accurate and honest information. Quality communication skills are an essential element in navigating these families through the cancer trajectory. Palliative nursing care extends across all treatment modalities, and patients undergoing palliative surgery and chemotherapy require rigorous support and care. Nurses play a critical role in patient and family communication, establishing goals of care and providing expert management of symptoms. There is a need for continued research to address this area of palliative care and for persistent advancements of clinical nursing expertise to best serve these patients and families. These include (1) the inclusion of outcomes that are patient- and family-centered and not only focused on clinical/surgical outcomes, (2) continued development of measures to evaluate high-quality care in palliative surgery and chemotherapy, (3) focus on communication and decision-making (i.e., preoperative advance care planning), and (4) evidence-based interventions to integrate palliative care principles into the routine care of patients in palliative surgery and chemotherapy.[4,77]

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CHAPTER 55

Rural Palliative Care

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and Marie A. Bakitas

Key Points

- Providing palliative care to persons living in rural areas across the globe presents significant barriers including transportation, geographical and economic challenges, and the absence of local palliative care experts and resources to meet the needs of patients with complex, serious illness.
- Telehealth, phone-based care, and specially trained lay community workers are some strategies being applied to increase access to palliative care in rural settings.
- Palliative care research, especially focused on the issues germane to rural culture and socioeconomic factors, is needed to address the specific evidence gaps for this unique environment.

Case Study: Lack of Access to Advanced Heart Failure Therapies

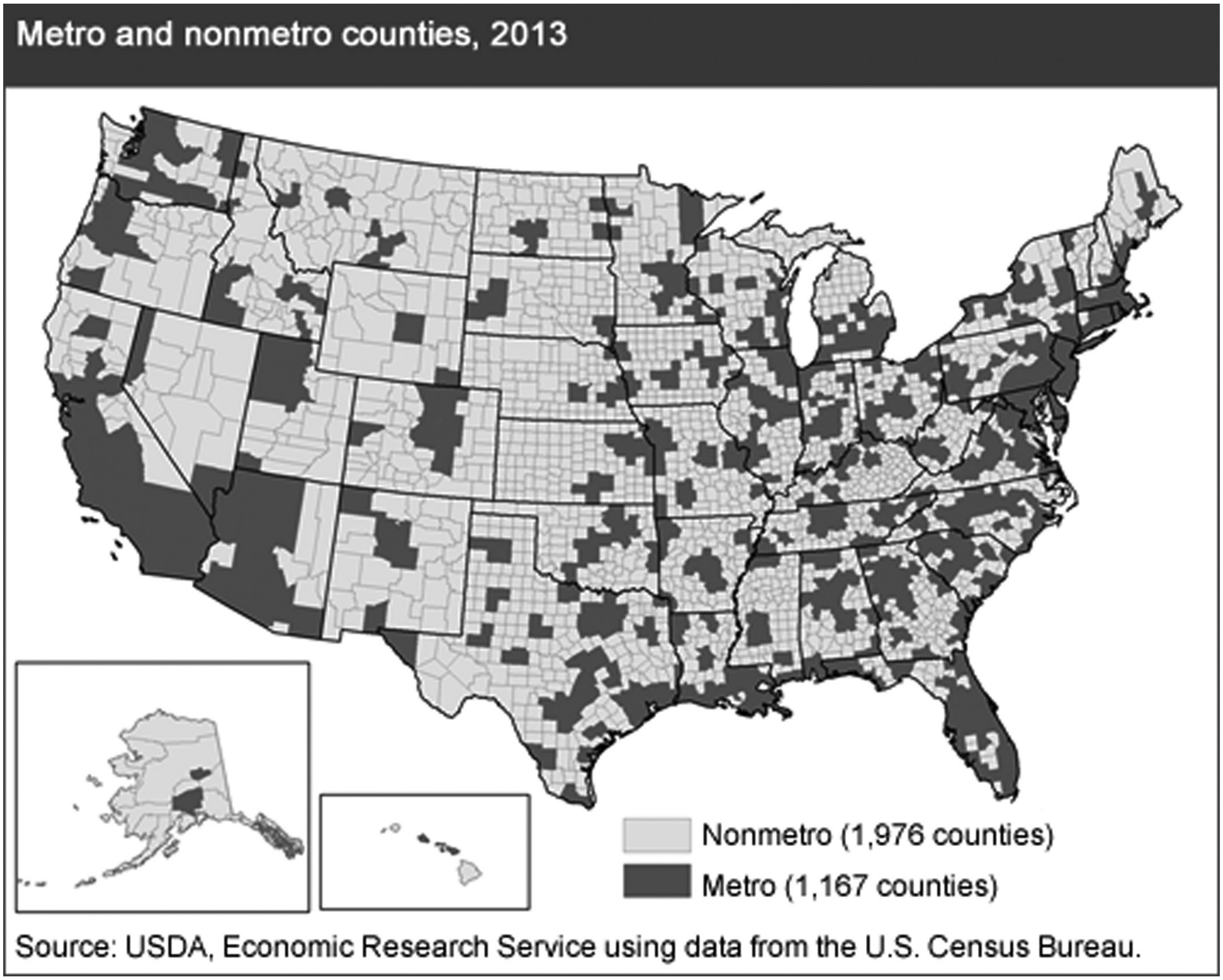
Denise is a widowed 62-year-old African American middle school teacher with a history of myocardial infarction, hypertension, and diabetes who was recently diagnosed with Stage D heart failure after an emergent admission for respiratory distress. Denise was flown by helicopter from her rural town's (pop. 5,000) critical access hospital to the tertiary care academic center as there were no cardiac specialists within 3 hours of her town. Denise was in the intensive care unit (ICU) receiving continuous intravenous inotropic support to keep her ejection fraction high enough to maintain her blood pressure and high-dose diuretic therapy. Denise's kidneys were still not perfusing well enough to maintain adequate urine output. The cardiologist believed that the best option to optimize her cardiac output and overcome her prerenal failure was a left ventricular assist device (LVAD). The home health agency serving her rural town was contacted, but they reported that none of their staff was trained in LVAD care. Palliative care had been consulted to discuss goals of care with Denise and her two adult daughters who lived in a different state. Denise was faced with a decision to consider hospice or to receive an LVAD that would require intensive daily maintenance without the hands-on assistance of home health and regular (weekly for several months) long-distance trips to the academic healthcare center.

Case Study: Lack of Access to Pediatric Specialists in Rural Communities

Charlotte is a 7-month-old twin who was born prematurely at 26 weeks' gestation. She and her twin sister were hospitalized immediately after birth in her local neonatal intensive care unit (NICU); however, within Charlotte's first week of life she developed necrotizing enterocolitis and was transferred to the only free-standing children's hospital in the state, 2 hours from her home in rural Alabama, for surgery to remove necrotic bowel. Postoperatively she remained in the distant NICU because she had only 12 cm of functional bowel remaining, had severe liver disease, and required long-term total parenteral nutrition. As her liver function declined, her symptom burden increased, and her illness trajectory was uncertain. Charlotte's only hope of survival was contingent on an intestinal transplant at 2 years of age; however, her medical team did not believe she would survive to the age of transplant candidacy. Charlotte's mother, a full-time daycare worker, and her father, a privately employed mechanic, struggled with visiting Charlotte more than 2 hours away from their home while also caring for her surviving twin who was now living at home but had chronic health needs. Because of Charlotte's serious illness, she was receiving pediatric palliative care. However, there were no specially trained pediatric hospice and palliative care providers in her rural community. If she was transferred to her community hospital where she would be closer to family, she would not have access to specialized pediatric or palliative care services.

Rural Palliative Care: What Is Different?

Globally, almost half of the population must overcome multiple factors, such as poverty, educational, and employment challenges that accompany rural living. In 2015, approximately 46.2 million US citizens (about 15%) lived in rural (also called "nonurban" or "micropolitan") areas (see Figure 55.1).[1] Nearly half (46.7%) of all people living in US rural areas (28 million people) are in the South.[2] However, depending on the definition, estimates of the rural US population can be as high as 40%.[1] Twenty-five percent of Europeans, 25% of Canadians, and 11% of Australians also reside in rural areas. Asia and Africa remain the most rural continents with 58% and 60%, respectively, of the population living in rural areas.[3] Box 55.1 provides additional information about rural definitions and rural health facts.



Source: USDA, Economic Research Service using data from the U.S. Census Bureau.

Figure 55.1 Nonmetropolitan counties include some combination of (1) open countryside; (2) rural towns (places with fewer than 2,500 people); and (3) urban areas with populations ranging from 2,500 to 49,999 that are not part of larger labor market areas (metropolitan areas). The US Census Bureau uses much smaller geographic building blocks to define rural areas as open country and settlements with fewer than 2,500 residents. Most counties, whether metro or nonmetro, contain a combination of urban and rural populations.

Two main challenges that persons with serious illness residing in a rural locale face are access to and acceptability of palliative care resources.[4–6] A number of reports found that living in US regions served by small rural hospitals put patients at high risk for limited or no access to hospice and palliative care services.[4,5,7,8] Only a quarter of US hospice programs are located in rural areas, and while hospice programs are increasing in general, hospice programs in rural areas are declining.[9] Even when palliative and hospice services are available, persons in rural and minority groups are less likely to use them, in part due to culturally insensitive healthcare systems and mistrust of healthcare providers.[10,11] Cultural mores about illness and death in indigenous and native populations differ significantly from the predominant Caucasian, Western traditions that are at the foundation of many palliative and hospice programs. Caxaj and colleagues'[12] scoping literature review identified priorities and challenges to providing palliative care to rural indigenous populations such as (1) environmental and contextual issues, (2) institutional barriers, and (3) interpersonal dynamics challenging client–clinician interactions. They recommended recognizing the essential role of family connections in building culturally based community partnerships to build palliative care capacity.[12] Hence, limited access and lack of culturally acceptable palliative and hospice resources are major challenges to providing equitable care to persons who are seriously ill and dying in rural areas worldwide.

Seriously ill rural patients are particularly vulnerable, may be socially isolated, and are at high risk to experience care disparities.[10,11,13] Long distances and low population density impose logistical and financial barriers that can impede specialty care access and diffusion of innovations such as comprehensive hospice and palliative care.[10] Local primary care clinicians are most often multiskilled generalists who may see few seriously ill or dying patients, thus limiting their ability to develop needed palliative care expertise.[10] In small rural communities with scarce palliative care

Box 55.1 Defining Rural

Sometimes population density is the defining concern; population thresholds used to differentiate rural and urban communities range from 2,500 up to 50,000, depending on the definition. Two commonly used methods for defining rural are described here.

Rural Urban Commuting Area Classification

The rural-urban commuting area (RUCA) codes classify US census tracts using measures of population density, urbanization, and daily commuting.

They are classified as:

Metropolitan (population 50,000 or greater)

Large Rural[a] (10,000 through 49,999)

Small Rural[a] town (2,500 through 9,999)

Isolated Small Rural[a] town (2,499 or less)

Urban, Urban Area, Urban Clusters, Rural

For the 2010 Census, an *urban area* comprises a densely settled core of census tracts and/or census blocks that meet minimum population density requirements, along with adjacent territory containing nonresidential urban land uses as well as territory with low population density included to link outlying densely settled territory with the densely settled core. To qualify as an urban area, the territory identified according to criteria must encompass at least 2,500 people, at least 1,500 of whom reside outside institutional group quarters. The Census Bureau identifies two types of urban areas:

- Urbanized Areas (UAs) of 50,000 or more people;
- Urban Clusters (UCs) of at least 2,500 and less than 50,000 people.

"Rural" encompasses all population, housing, and territory not included within an urbanized area or urban cluster (http://www.census.gov/geo/reference/ua/urban-rural-2010.html).

Facts about Rural Health Issues

- Rural employment has risen modestly as the national economy has recovered since employment levels bottomed out in 2010. Increases between 2013 and 2015 were 1.3%.
- Poverty rates in both rural and urban areas fell slightly in 2014 and more markedly in 2015—by 0.9 percentage point in rural areas and 0.8 percentage point in urban areas—but remain well above pre-recession levels.
- Population growth was uneven across rural and small-town America: more than half of the 2,053 urban counties lost population, whereas in more than 350 others, population growth was higher than the national average rate of 0.7%.
- Rural America had just over 46.2 million residents in July 2015, a slight decrease since 2010. The rural population declined by 136,000 or 0.3% between 2010 and 2014 but leveled out in 2015.
- The rate of rural population growth in America has slowed dramatically since the onset of the housing mortgage crisis in late 2006 and the recession a year later.

[a] Rural is also categorized/known as "micropolitan" in some US government schemas.

Source: From Reference 139.

Table 55.1 Percent of Medicare decedents who used hospice services

	2000	2015
Urban	24.3	49.7
Micropolitan	18.5	44.9
Rural, adjacent to urban	17.6	44.4
Rural, nonadjacent	15.8	38.8
Frontier	13.2	33.8

Source: From Reference 9, table 12-2.

resources, clinicians may also face the challenge of being called on to care for their own family, life-long friends, and neighbors at their end of life.[10,14]

Rural location has often been related to less and later hospice use (see Table 55.1) and higher rates of hospitalization at end of life,[10] particularly in rural nursing home residents.[15–17] Most rural patients are unlikely to have access to the "gold standard" interdisciplinary team (IDT) provided by palliative and hospice services.[18,19] Hence, these patients may have to choose between "going without" or being transferred to a distant site for care.[10] Patients transferred to distant tertiary care settings are at high risk of spending their last days or weeks of life far from home and loved ones. Rural patients with advanced disease, severe pain, or related symptoms who remain in a local facility may suffer during their last weeks of life because state-of-the-art techniques for treating pain or other causes of distress are scarce. The opening cases provide vivid examples of the suffering that can occur when local specialty resources are not available at end of life.

Challenges to Providing Palliative Care in Rural Settings

Box 55.2 lists the numerous challenges and barriers to accessing and providing rural palliative care.[10–12,20–25] These barriers can include patient, provider, and health system factors. Patients and their family caregivers may be fearful of traveling to receive care from unfamiliar providers even though local providers may lack adequate expertise to provide state-of-the-art palliative and hospice care. Clifford and colleagues' survey of 23 community cancer centers identified lack of physician acceptance as a major barrier; in communities with palliative resources, only 17% of patients were referred.[26] In that survey, physicians believed that patients' needs were already being adequately addressed without the addition of palliative care services.[26] Physician "gate-keeping" (i.e., lack of referral of patients for palliative care services) is not unique to rural settings; however, the extent of this phenomenon needs to be more fully explored. If a trusted physician does not recommend palliative services, then patients and family members are unlikely to seek them out. Rural geography can be isolating,[20,23,27] making visits infrequent and creating difficulty in providing a rapid response to patients and families in distress.[8,10,11]

Inadequate rural clinician education can limit knowledge of best palliative care practices.[28–31] Therefore, access to distance education, online resources, specialty journals, and textbooks is essential. However, learning complex palliative care communication techniques may be best acquired through in-person and role-play strategies, which may not be readily available.[31,32] A comprehensive review found very little research on the best

Box 55.2 Barriers/Challenges to Rural Palliative Care

Patient/Family

Lack of patient/family knowledge and acceptance of palliative care

Lack of transportation and long travel distances to palliative care centers (for patients and family/friend visitors)

Patient/family preference to stay in home community for care

Patient/clinician concerns that they will lose touch with community providers if they seek care at centers far from home

Mistrust of unfamiliar providers

Provider

Limited community clinician access to palliative care experts

Limited community clinician exposure to palliative care patients in their practice (e.g., inadequate primary palliative care skills)

Limited availability of palliative care education in the community

Limited scope of practice (e.g., inability of advanced practice practitioners to admit patients to hospice, prescribe opioids)

Health System/Policy/Regulatory

Poor communication/coordination of care between academic and rural community settings

Limited evidence of palliative care benefits in rural palliative care

Lack of availability of technology/techniques used for complex patients (e.g., pain pumps, left ventricular assist devices (LVADs)

Scope of practice and regulatory disincentives

Source: From References 10, 11.

ways to provide quality palliative care education that actually had an impact on patient outcomes. Further distance and interactive learning approaches for nurses were also scarce.[31] These authors recommended the need for more research on palliative care education best practices in information technology targeted to meet the needs of rural learners.[31]

Delivering Rural Palliative Care beyond the United States

Outside of North America and Europe, research on rural palliative care is sparse, but existing studies highlight many common experiences and challenges.[10,20,33–39] In developing and industrialized nations, the demand for palliative care services in rural areas far outweighs the supply, and this disparity is increasing.[40] This widening gap corresponds to an increase in average life expectancy; however, these populations are living long enough to acquire serious, chronic illnesses.[41] In rural communities, lay people may provide the bulk of palliative care services.[11] European,[39,42,43] South African,[37,44] and Australian[45–47] studies report limited formal palliative care training programs and a high demand by generalists, who may feel underprepared. As in the United States, successful programmatic efforts have prioritized mentoring and educating local community home care providers and volunteers in delivering palliative care,[48–50] rather than developing centralized, urban centers attempting to serve rural areas. Unfortunately, similar to the United States, these services are usually provided only at the very end of life after all curative treatments have been exhausted.[12,20,51,52] Hence, the patterns of underutilization and late timing of palliative care are equally prevalent.[53]

Rainsford and colleagues'[11] review of 22 studies of rural end-of-life (EOL) care across both developed and developing countries found that long geographic distances to specialized palliative care was the greatest negative influence. Rural residents in developing countries, particularly indigenous populations who valued highly dying in their community, also found it very challenging to coordinate visiting palliative care and other home health services to come to their communities. Overarching themes for rural dwellers regardless of country of residence was receiving personalized care that demonstrated "presence," honoring their customs and ways of making meaning, and having generous volunteer support from local community members.

Although many challenges in rural settings outside of the United States are similar, in developing nations, they are often more pronounced and extreme. This is partly because the public and healthcare infrastructure of many developing nations is markedly less amenable to the delivery of palliative care services and medications in remote areas. Examples include insufficient inventory or lack of access to pain medications, especially opioids,[11,54–56] severely decrepit or nonexistent highways and roads combined with considerable distances between remote areas, limited legal scope of practice for nurses resulting in the inability to administer pain medications, [57] and physical dangers including fear of violence and infectious disease, particularly for home care providers.[52] Thus, the role demands of the palliative care clinician or team are often vastly greater in scope and can include providing food, shelter, and transportation.[11]

Taboos can also often be extreme: for example, Singer et al.[58] note that Israeli Bedouins seldom speak the word "cancer" because there is great shame associated with having this illness. The shame is such that a Bedouin girl of a family where someone has cancer may have difficulties marrying. In another study, Campbell[59] found that male palliative care health workers in South Africa were perceived by female patients as more likely to perpetrate physical abuse, thus hindering the delivery of palliative care. Finally, the types of life-threatening illnesses addressed by palliative care clinicians in foreign rural areas are often not the advanced cancer and heart failure populations seen in the United States and other developed countries but instead are patients with HIV/AIDS and tuberculosis, as is prevalent in sub-Saharan Africa.[52] All this said, such stark contrasts in rural palliative care are more salient when the distinction is between industrialized and developing countries as opposed to the United States and all other countries.

Creative Strategies to Meet the Palliative Care Needs of Rural Patients

Technology-Enabled Healthcare

A major challenge to palliative care delivery in rural areas is the need to provide high-quality care across distances with limited resources. A wave of new strategies that capitalize on eHealth or technology-enabled approaches has great potential in improving palliative care for rural environments. Technology-enabled health is a synergy between the fields of telehealth, mobile health, electronic health informatics, informatics, and health information exchange. The overall goal is to improve access and care quality in a cost effective environment.[60]

Remote monitoring involves the use of devices that transmit data in real time or that can be later downloaded to a providers' office or computer. A trial of remote symptom monitoring overseen by a nurse in which cancer patients used a web-based method to report on 12 symptoms was found to improve quality of life (QOL) and 1-year survival in patients with metastatic solid tumors receiving chemotherapy treatments compared with usual cancer care.[61] Community-based models in which providers go to patients' homes to provide palliative care services have been developed specifically to address the needs of patients in rural and remote areas.[62] ResolutionCare, a professional corporation in Northern California developed by Michael D. Fratkin, in 2014, was created from a successful crowdfunding campaign to provide home-based palliative care via home visits and videoconferencing. It uses an IDT to see patients within a 150-mile radius of a physical office (patients are not seen in the office).[63] They also provide palliative care "telementoring" in partnership with Project ECHO (Extension for Community Healthcare Outcomes) to train healthcare practitioners to provide primary palliative care.[64] Project ECHO is a telehealth model that links rural primary care clinicians with specialists to perform real-time learning using inexpensive videoconferencing technology. The program's novel approach allows physicians, nurse practitioners (NPs), and other clinicians to jointly manage complex illness and promotes the use of best practices while enabling patients to receive treatment in their home communities.

Using Telehealth to Increase Access to Palliative Care

Telehealth uses advanced information and communication technologies to improve access to care. Telehealth is a heterogeneous collection of clinical practices, technologies, and organizational arrangements that can be grouped into three categories (see Box 55.3). Telehealth strategies have been found to be cost-effective and have been associated with high-quality clinical outcomes and patient satisfaction in a variety of pediatric[65–67] and adult palliative care settings.[24,68] Barriers to telehealth, such as start-up and maintenance costs and concerns over equipment costs, privacy, and security, have begun to decrease. Furthermore, adoption of electronic medical records has contributed to staff training and comfort levels with telehealth. Though technology may be seen as dehumanizing and impersonal, conflicting with core principles of palliative care,[69] increasing evidence demonstrates that it is possible to overcome these barriers, and high satisfaction has been reported as telehealth improves access to palliative care.[70] Palliative care telehealth approaches being implemented in rural areas around the world can provide access to consultations, education, and collaboration for providers, patients, families, and caregivers.[60,71–76]

Monitoring and measuring health data over geographical, social, and cultural distances is being facilitated by the use of smartphones and an explosion of wearable technology, monitoring devices, and mobile applications available for almost any health and illness condition.[77] The Health Information Technology for Economic and Clinical Health (HITECH) Act, enacted by Congress in 2009, accelerated the adoption of meaningful use of information technology (IT) for clinical purposes.[78] The HITECH Act defined meaningful-use objectives for participants in Medicare and Medicaid programs aimed at improving quality, safety, efficiency, and care coordination; engaging patients and families; improving public and population health; and ensuring privacy and security for personal health information. In 2003, the Federal Communications Commission (FCC) funded a rural healthcare support mechanism to expand access to broadband, especially in rural areas. This was intended to encourage the creation of healthcare networks and use of technology to improve care, lower costs, and improve patient experiences.[79] The use of information technology and mobile applications continues to grow.[80]

Box 55.3 Types of Telehealth Technology

There are three main categories of telehealth technology: remote patient monitoring, store-and-forward, and real-time audio/video encounters.

Remote Patient Monitoring

Remote patient monitoring, sometimes called *self-monitoring* or *self-testing*, is a means of monitoring patient health and clinical information at a distance. It helps to simplify patient adherence to testing and it lowers the cost of frequent monitoring. It is often used to treat and manage chronic illnesses like asthma, cardiovascular disease, and diabetes.

Store-and-Forward

Store-and-forward is the oldest form of telehealth technology. It refers to the transmission of images or information from one provider to another. An example of store-and-forward telehealth technology is when a clinician sends a digital image of an x-ray to a radiologist for analysis. State telemedicine reimbursement laws, even in states that require parity for real-time communication, do not always cover store-and-forward telehealth.

Real-Time Audio/Video Communication

Real-time communication is what many consider the most common use of telehealth technology. An example is when a patient is at one location and the provider is at another and they connect using a video-enabled device and a telephone or computer audio. Patients may be at a healthcare facility with a provider, and they establish communications with a specialist at a remote location, or a patient might not be at a medical office but at home or in a state health department office. Many state laws require insurers to reimburse for these types of video visits. Most don't have a similar requirements for telephone calls that don't involve video.

Source: http://telehealthdirectory.org/; http://www.cchpca.org/what-is-telehealth

A collaborative model using Internet-conferencing between a rural palliative care NP and an urban palliative care physician expert was able to improve access for underserved patients and families. A Canadian study used regional palliative care experts to provide telehealth assessments and coordinate with local providers to improve symptom management.[72] A Canadian province developed a 24-hour telephone hotline to provide expert palliative care consultation, which was most frequently accessed by rural communities.[81]

Canada's Rural Palliative Telehealth Project,[81] aided by provincial and national funding, examined telehealth to conduct direct palliative care consultations and care conferences with distant primary care teams, deliver staff education, and link rural patients with their urban specialists for palliative care case conferences. Often difficult treatment decisions could be discussed and future plans established without the need to travel to an urban center. Telehealth was beneficial for discharge planning between the urban tertiary palliative care unit and the rural care team when patients with complex issues were being transitioned back to their home communities.[81]

Remote monitoring, in combination with the application of adult learning and cognitive behavioral theories applied to telehealthcare delivery and practice, can promote improved patient self-efficacy with disease management.[82]

Project ENABLE (Educate, Nurture, Advise, Before Life Ends) was an early use of telehealth to provide early concurrent oncology palliative care.[83,84] ENABLE, based on the World Health Organization continuum of care[85] and Wagner's chronic illness care[86,87] models, includes a face-to-face standardized palliative care consultation and a nurse-coach delivering the standardized "Charting Your Course" curriculum (see Table 55.2) to patients and care partners. Approximately 1,000 patients with cancer (and their family caregivers) have participated in ENABLE clinical trials. Published trial results have demonstrated gains in QOL, improvement in symptoms, less depression, and improved survival.[68,83,88] The primary focus of ENABLE is coaching patients to learn new skills of problem-solving, patient empowerment and activation, proactive symptom management, healthcare decision-making, advance care planning, communication, and legacy/life review. Another feature is assisting the patient and family to identify local, community primary care, and palliative/hospice resources to reduce dependence on distant care providers and allow them to stay in their home communities. Family caregivers participating in the program report lower depression scores and lower burden.[88] Others have also found telehealth to be an important resource for family caregivers who have generally expressed satisfaction with this approach.[89]

Table 55.2 ENABLE Charting Your Course curriculum

Patient curriculum	Caregiver curriculum
Module 1 (week 1) Behavioral Activation/Problem Solving	**Module 1 (week 1)** **Caregiver Role** **COPE** attitude and problem solving
Module 2 (week 2) Symptom Management	**Module 2 (week 2)** Self-care
Module 3 (week 3) Decision-making, Communication & Support	**Module 3 (week 3)** Being a partner in symptom management
Module 4 (week 4) Life Accomplishments & Goals and Life Review	**Module (week 4)** Focus on **decision-making**
Module 5 (week 5) Accomplishments and Future Goals/ Forgiveness	Planning for follow up **Monthly & bereavement follow-up**
Module 6 (week 6) Unfinished Business/Leaving a Legacy	
Monthly follow-up	

The Veterans Health Administration (VHA) began the VA Hospice and Palliative Care initiative in 2002, collaborating with the National Hospice and Palliative Care Organization to improve care to veterans and families. In addition to establishing hospice and palliative care teams in all its medical centers, the initiative developed a telehealth model to provide holistic EOL care. The Advanced Illness/Palliative Care (AIPC) program utilized text messaging and videophones to monitor patients and provide symptom management and spiritual support. Participants reported that technology helped them feel more connected to the care team.[90]

Telehealth may provide an opportunity for the limited number of specialty trained pediatric palliative care providers to educate, consult, and manage seriously ill children in rural areas. For example, a case report of rural pediatric palliative care patients followed by a hospital-based pediatric palliative care team found that patients and families found it to be helpful, especially for receiving counseling that would normally not have been available.[65] Although broadband may not be universally available, many rural communities can obtain Internet access in community clinics and thus can access telehealth services. In the case of pediatric palliative care, where specialization is such that most rural areas would otherwise lack services, telehealth may be able to reduce disparities.[65–67,91]

In 2015, the American Association of Retired Persons (AARP) conducted an online survey of 1,028 US family caregivers about how they use mHealth, telehealth, and other technologies and what their interests were in technology solutions to potentially meet their caregiving needs.[92] The survey found that 71% of caregivers were interested in technology to assist with their caregiving but that only 7% were currently users, indicating a wide gap between demand and use. The biggest barriers to technology use by caregivers was a lack of awareness about available technologies, cost, and the time it would take to learn a new technology and incorporate it into their everyday routine. The report indicated that technology use among younger caregivers was higher than older caregivers (8.5% vs. 4.6%), and thus technology use in caregiving was likely to rise over the coming decades. The tasks that caregivers would like to see technology assist them with the most included monitoring a loved one, helping them manage medications, and care coordination that is seamlessly integrated across platforms.[92]

Web-Based Resources

Palliative care resources are available through the Internet to anyone with electronic access. The Center for the Advancement of Palliative Care (CAPC.org) offers Internet-based educational programs and links for patients and caregivers. The American Academy of Hospice and Palliative Medicine (AAHPM.org) and the Hospice and Palliative Nursing Association (HPNA.org) offer online resources. Healthcare networks and advocacy groups are using electronic media to make educational programs available to healthcare providers, patients, caregivers, and the general public. The National Hospice and Palliative Care Organization has resources for rural providers available online at https://www.nhpco.org/access-outreach/resources-rural-providers. In Australia, oncology specialists developed an educational program on palliative oncology for health professionals that focused on the needs of rural providers. Participants reported that they improved their knowledge, and 75% planned to review or change their practice as a result.[74] The Minnesota Rural Palliative Care Initiative partnered with rural communities to expand access to palliative care using web-based educational sessions, a dedicated web page with resources for program development, links to national guidelines, clinical tools, and shared draft documents.[71]

Developing Clinical Capacity in Rural Palliative Care

As the population over age 65 doubles by 2030, with the highest numbers being in the rural areas as they "age-in-place," a shortfall is projected over the next 20 years for many physician specialties.[93] The older US rural population compared to those in urban areas are female, live in higher poverty, have more chronic conditions and disability, and have a lower QOL due to health conditions.[93,94] The elderly are the largest population to use palliative care services, so the growth in their numbers will further strain their access to palliative care.[10] Distribution of palliative care resources is noted to vary by geographic region, and globally is inaccessible to a majority of the country's population, with rural regions most frequently underserved.[95–97] As the need for medical services expands in the coming years, the IDT and addressing statutory laws limiting NPs' and physician assistants' scope of practice[10] will be increasingly important, including in palliative care and particularly in rural areas.[98] The palliative care workforce issue among physicians is well-defined, with conservative models estimating the current shortfall at between 6,000 and 18,000 physicians. This prediction has not taken into consideration the anticipated growth in palliative outpatient care.[99] The mismatch between the predicted increase in palliative care–eligible patients and the physician workforce by 2030 results in a ratio of 1 physician for every 26,000 patients, certainly an impending crisis.[100] Providers receive sparse formal education in graduate or medical school and are unprepared for the complex life-limiting disease conditions and associated symptom management of patients in palliative care, resulting in patients suffering.[101] Enhancing palliative care education and skills at the early learner level and with policy support to mandate inclusion of palliative care content in all training programs should increase the number of physicians with adequate training to address primary palliative care needs.[102,103]

The Institute of Medicine[60] has called for nurses to fill new and expanded roles to increase access to care. However, the workforce is "graying" and approximately 40–48% of palliative care nurses are over 50 years of age. A large number of nurses are expected to leave the workforce in the next 10–15 years, with few replacements, thus leaving a significant gap in care.[104] The use of palliative care–trained advanced practice registered nurses (APRNs) to lead consult services[105] and to be integrated into routine intensive care units teams[106] and pediatric care teams[107] is growing. APRNs have also led the way in providing outpatient care and acting as IDT coordinators.[108] A Pennsylvania health network utilized NPs to provide home-based nonhospice palliative care consultation that improved access to palliative care and reduced inpatient costs for EOL care.[109] The VA model for palliative care has also successfully used advanced practice registered NPs.[110] The HPNA offers educational programs, promotes networking, and provides for specialty certification for APRNs (www.HPNA.org). As more APRNs are added to the workforce, they are improving access to quality palliative care.

Lay Health Workers

Given that most persons with chronic or serious illness are located in community settings[99] and the relative scarcity of outpatient palliative care support,[111,112] strategies to address the palliative care needs of persons living in rural areas must include innovative health services. Lay health workers (community health advisors or community health workers) have been effective in serving as a bridge between healthcare institutions and the community, disseminating public health, and providing healthcare services including behavioral strategies and interventions to improve health outcomes.[112,113] Community health workers trained in palliative care principles can have a role in delivering components of palliative care, including advance care planning, in regions where access to formal healthcare systems with palliative care resources is limited.[112,114,115] In developing countries, volunteer community health workers have been trained in the basics of palliative care and supported in the delivery of that care. Evaluations have found these programs to be beneficial to both patients and the volunteer health worker.[112,116] In some areas, community health workers include health system "navigators," thus extending the role of the lay navigator to help in the reduction of cancer disparities by encouraging early screening and prevention in high-risk groups across the entire palliative care spectrum.

The effectiveness of this approach has been demonstrated in some established cancer navigation programs. The Deep South Cancer Navigation Network demonstrated important gains in cancer screening rates, especially among African American women, using community health workers in the Deep South.[117] The University of Alabama at Birmingham (UAB) Health System Cancer Community Network (CCN) trained nurse and lay navigators (community health advisors) in palliative care principles including communication skills related to conversations and decision-making about advanced disease and in symptom recognition and advocacy to reduce barriers to cancer care.[118,119] The program was feasible and demonstrated improved self-efficacy in the lay navigators after training, a significant increase in advance care planning discussions in the African American population, identification and resolution of psychosocial distress, and a statistically significant decline in Medicare spending, emergency room visits, and hospitalization over time.[119–122] In rural regions with high levels of hospice penetration, lay health workers may also be engaged as "sitters." "Sitters" are persons without formal medical training who may assist in the care of a seriously ill person by providing companionship, assistance with activities of daily living, and assistance with other practical and logistical issues. Persons with limited healthcare training (in the United States identified as certified nursing assistants [CNAs] or in Canada they may be personal service workers [PSWs]) have a role in caring for persons with chronic and serious illness and fill a gap in service in a rural setting.[123,124] Data from Canada and Great Britain indicate that these workers find caring for palliative care patients challenging,[125] but no data were identified related to workforce capacity or rural locations in the United States. Hospice and palliative care volunteers in rural regions may also have an expanded scope. This expanded role of volunteerism provides valuable assistance while interacting with both informal and formal caregivers of palliative care and hospice patients.[102] The available literature indicates that, in rural regions, support for palliative care patients may include a complex web of individuals including informal caregivers, community volunteers, and trained healthcare workers who form an organic and site-specific network of caring for the seriously ill and dying.[126,127] While evidence supporting lay health workers in palliative care and hospice is sparse, it is expanding in capacity for the provision of palliative care in rural regions.[128,129] Important areas for research include defining the role that community health workers or community health advisors may play in enhancing access to palliative care in rural regions. Understanding the potential impact of using lay personnel on palliative care outcomes and defining the best way to integrate training for this potential new workforce in rural palliative care should be active areas of investigation.

The Role of Critical Access Hospitals

Rural hospitals provide essential healthcare services to nearly 54 million people, including 9 million Medicare beneficiaries, low-income individuals, and Medicaid populations who are often in need of palliative care services. With the closure of 63 rural hospitals between 2010 and 2015, 1.7 million people are at higher risk for poor health outcomes due to lack of local access to acute care.[130] Rural hospitals care for, on average, a higher percentage of Medicare patients since rural populations are typically older than average urban populations.[131] Medicare reimbursement issues, sustained workforce shortages, rising healthcare insurance costs, aging rural hospital facilities, and the demand for expensive new information systems all contribute to the daily challenges of providing adequate care in rural settings. To deal with some of these issues, in 1997, through the Balanced Budget Act (BBA) of 1997, a designation of Critical Access Hospitals (CAHs) was developed that would receive cost-based reimbursement. To be designated a CAH, a rural hospital must meet defined criteria, such as 24-hour emergency services, a medical provider on premises or the ability to be there within 30–60 minutes, an annual length of stay of 96 hours or less, less than 26 beds, and an established referral/transfer policy and agreement with an acute care hospital (see Box 55.4).[132,133]

Box 55.4 Critical Access Hospital Criteria

- Must be rural, located within a state participating in the Medicare Rural Hospital Flexibility program
- Must be more than a 35-mile drive from any other hospital or critical access hospital (CAH) (or, in the case of mountainous terrains or in areas where only secondary roads are available, more than 15 miles from any other hospital or CAH)
- Must have 15 or fewer acute inpatient care beds (or, in the case of swing bed facilities, up to 25 inpatient beds that can be used interchangeably for acute or skilled nursing facility-level care, provided no more than 15 beds are used at any one time for acute care) as reported on the cost report
- Must restrict patient length of stay to no more than 96 hours unless a longer period is required because of inclement weather or other emergency conditions, or a physician review organization (PRO) or other equivalent entity, on request, waives the 96-hour restriction (the 96-hour length-of-stay limitation was modified in 1999 to a per-patient annual average)
- Must offer 24-hour emergency services
- Must be owned by a public or nonprofit entity (modified in 1999 to extend eligibility to for-profit hospitals)

Source: From Reference 140.

The goal of CAHs can at times be at cross-purposes with the goals of palliative care. For example, there is a financial incentive for brief stays to essentially stabilize and transfer the patient to a larger hospital or academic center.[133] In many cases, for these chronically ill, older adults, the more appropriate approach would be to establish goals of care and identify appropriate local care resources rather than transfer these patients to academic centers from which they might not ever return. In many cases, it might be more appropriate for these rural hospitals to keep patients for EOL care or to stabilize the patient and, if possible, arrange for return home with hospice care. The nursing and medical staff at the CAH are expert generalists. The nurse may be the first point of contact for the patient and family in the CAH, being responsible for assessing and stabilizing the patient before transfer to the urban hospital. The traditional multidisciplinary specialty palliative care team is rarely available at a CAH, but it is generally available at the urban hospital to guide and coach the rural staff throughout the process. This collaboration is an opportunity to extend palliative care through the local rural providers to the patients they serve.[133]

Creating Academic–Community Partnerships and System-Wide Improvements

Patients with palliative care needs located in rural or isolated areas have been able to take advantage of local community resources and to rely on local primary care and other clinicians through partnerships with an academic or other palliative care program that is well-resourced. Access to palliative care resources to meet rural, indigenous communities' needs remains a challenge, but progress in partnerships to address their unique social, cultural, and geographic needs and barriers to care is being made.[96,134] A guide developed by the Health Research and Educational trust for small and rural hospitals in the United States focuses on strategies to improve care by concentrating on better population health management. This is achieved through well-structured relationships between rural hospitals and community care partnerships.[131] This is best achieved through a continuum of types of population health partnerships: (1) networking, (2) coordination, (3) cooperation, and (4) collaboration.[131] The reader is referred to the guidebook *The Role of Small and Rural Hospitals and Care Systems in Effective Population Health Partnerships* for excellent resources in developing such relationships (available at http://www.hpoe.org/small-rural-partnerships).

In the United States, there are palliative care programs that serve as tertiary centers. These centers should have, as part of their mission, strategies to bring their expertise to the community. Using community capacity development theory, a learning collaborative model, and focusing on the National Quality Forum *Consensus Report: National Framework and Preferred Practices for Palliative and Hospice Care Quality*, a partnership called the Minnesota Rural Palliative Care Initiative (MRPCI) was formed between Stratis Health, an independent nonprofit organization, and Fairview Health Services' palliative care program. The goal was to improve care across 10 rural communities. The MRPCI partnered with rural communities to expand access to palliative care using web-based educational sessions, a dedicated web page with resources for program development, links to national guidelines, clinical tools, and shared draft documents.[71,135]

Another innovative partnership was the Centers for Medicare and Medicaid Services Healthcare Innovation (CMMI) awarded to Four Seasons Compassion for Life in Western North Carolina (WNC). This innovation award was to extend the existing community-based palliative care model to increase inpatient and outpatient interdisciplinary palliative care services from 4 to 24 counties in WNC and parts of South Carolina. The number of collaborating facilities (skilled nursing, community hospitals, etc.) were markedly increased through this award. The program's community educators traveled to various sites in these states to educate community groups, churches, providers, and others about the program and how to refer patients to the program. The outcomes indicate that the community-based palliative care model is scalable and that the efficiency and effectiveness of a program is increased by implementing a risk-screening and referral guide that aligns patients and local community resources to address their biopsychosocial needs.[136]

Clinical and Research Implications

There have been many outstanding efforts made in the past two decades to improve and articulate standards for the emerging specialty of palliative care.[137] Yet existing guidelines and models of palliative care delivery have mostly overlooked a key multifaceted variable that is critical to achieving better outcomes at the population level: that of geography and the unique obstacles faced by palliative care clinicians delivering care to rural populations. When it comes to disparities in palliative care, *where* one lives matters. Overlooking this reality can result in an underappreciation of the differences between rural and urban populations that significantly impacts the approach one takes in delivering optimal palliative care. As illustrated in this chapter and described in a number of reviews,[1,10,11] rural populations in comparison with urban populations have proportionally more older adults over 65, higher unemployment rates, higher numbers of uninsured, higher numbers of individuals below the poverty line, greater sensitivity to economic downturn, lower population densities, longer travel distances to healthcare facilities, fewer numbers of healthcare specialists and generalist providers, narrower scope of available healthcare services, higher rates of chronic disease, and, in the United States, greater dependence on Medicare and Medicaid.

Accounting for these and other unique characteristics of rurality, the question is how palliative care clinicians and researchers should respond. For palliative care clinicians, the priority challenge will be to ask explicitly about and address any misperceptions about palliative care expressed by rural patients and families and local generalist providers. We recommend that this be a requisite item of discussion with any new interaction or consultation with patients, families, and providers. Clinicians might also consider taking a more proactive approach and initiate regular check-ins with generalist providers in outlying areas to offer expertise and consultation on difficult cases in their areas. CAPC now has national Palliative Care Leadership Centers (PCLC) focused on developing community-based palliative care programs beyond the hospital setting. This program provides online curriculum, webinars, virtual office hours with palliative care experts, onsite training, and more, all focused on incorporating palliative care into the local practice patterns of the community providers.[62,69,138]

For palliative care researchers, a change in perspective is needed, one that migrates from the familiar territory of health as seen at the pathophysiological, individual, and social levels to the more uncharted terrain of palliative care at the level of living conditions, communities, geography, and social and economic policies and climates. Given the growing use, prevalence, and capabilities of communications and other technologies, researchers are called on to propose and test innovative solutions that incorporate the use of such technologies to overcome many of the geographical obstacles of rural healthcare delivery. If but one message comes across, we hope to convey that where one lives makes a huge difference as to whether or not a patient and family receive adequate palliative care.

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CHAPTER 56

The Role of PT, OT, and Other Therapies in Palliative Care for Seriously Ill Patients

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Key Points

- Progressive loss of function and increasing symptom burden throughout varying stages of a terminal illness have a profound impact on patients and their caregivers, presenting an essential need for rehabilitation.
- Palliative rehabilitation is guided by the following key principles: communication and collaboration, addressing disability, easing symptom burden, adapting through all stages of illness, and cultivating quality of life.
- Rehabilitation can assist in managing fatigue, pain, dyspnea, dysphagia, anxiety, and depression through the primary disciplines of physical therapy, occupational therapy, speech language pathology, and recreation therapy.

Introduction

This chapter defines the roles of each rehabilitation discipline and describes what each service offers in the realm of palliative care. The approaches of palliative rehabilitation and the interventions that address different aspects of function and quality of life (QOL) will be detailed, with the goal of supporting interdisciplinary collaboration between nurses and rehabilitation therapists.

Case Study: A Patient in Rehabilitation Therapy

At age 58, JP was diagnosed with non–small cell lung cancer after his oncologist confirmed stage II disease with a right upper lobe mass. JP had hoped that his initial treatment of chemotherapy would allow him to reach a state of remission; unfortunately, however, he responded with mixed results, with the cancer continuing to spread following several months of subsequent lines of therapy. He and his family struggled with the aggressive nature of the disease as he experienced progressive decline in health and losses in function. Understanding that aggressive treatment was no longer viable, JP decided to focus on palliative treatment to be able to spend his remaining life with greater comfort and purpose.

JP's cancer had gradually damaged his spinal cord and recurrent laryngeal nerve, resulting in lower extremity weakness, shortness of breath, persistent fatigue, hoarse voice, and risk of aspiration. As a result, he could no longer continue working as a construction manager, maintain his home, or fully engage in his favorite activities of coaching boxing and hosting family barbecues. He lost self-confidence in maintaining his safety, prompting consultation with the rehabilitation team to address his impairments. Throughout outpatient visits and inpatient stays, he worked with his therapists to prevent further disability and adapt to the challenges that impacted his daily life.

During JP's final admission for a clinical trial and palliative radiation, the rehabilitation team provided him a great benefit that positively altered his experience of palliative and end-of-life care. Despite becoming bed-bound from paralysis, dependent on a feeding tube, and eventually transitioning to hospice, his rehabilitation team played a key role in helping him function as well as possible to maintain the highest possible QOL.

The Role of Rehabilitation

Palliative Rehabilitation

Progressive loss of function and increasing symptom burden throughout varying stages of a terminal illness have a profound impact on patients and their caregivers, presenting an essential need for rehabilitation. Interdisciplinary palliative care includes rehabilitation, which provides patients with the opportunity to address specific functional impairments and adapt to each stage of illness. The rehabilitation team can assist nursing and the care team to offer additional support to patients and caregivers to achieve their functional goals and improve the quality of their care.

The role of rehabilitation in palliative care is to help patients maintain or maximize their independence and enhance their QOL as it relates to patient and family priorities.[1] Palliative care addresses common symptoms including fatigue, pain, dyspnea, dysphagia, anxiety, and depression, which can result in a decline of overall function.[2] If not addressed, this symptom burden can lead to impairments in mobility, daily activity, coping, and caregiver burden, causing decreased QOL.[2] Rehabilitation can assist in managing these conditions through the primary disciplines of physical therapy (PT), occupational therapy (OT), speech language pathology (SLP), and recreation therapy (RT). Each discipline provides its own expertise in evaluating impairments and implementing specialized interventions to maximize function and reduce symptoms.

Despite a clear need for rehabilitation within palliative care, palliative rehabilitation is often underutilized in actual practice.[3] This is due to a limited understanding of palliative rehabilitation held by the interdisciplinary team as well as the assumption that terminally ill patients do not require or benefit from rehabilitation.[3] Palliative rehabilitation goes beyond the common misconception that therapy only consists of exercise. Rather, it delivers a diverse approach that addresses multidimensional aspects of the patient's physical, social, emotional, and spiritual well-being.[3] Patients with advanced cancers undergoing a structured palliative rehabilitation program can experience improvements in physical endurance and mobility, decreases in symptom burden, and creation of social support systems.[4] Palliative rehabilitation can also benefit patients with cardiovascular, pulmonary, or neurological diseases; improve coping; and decrease caregiver burden.[1]

Nurses play a key role in screening and identifying those who can benefit from palliative rehabilitation. Patients can be screened using a variety of functional assessments (e.g., Karnofsky Performance Score, Palliative Performance Scale) as well as tools that assess for safety and fall risk. While palliative rehabilitation can be initiated at any point during patients' trajectories, earlier integration of these services can result in better care.[4] These services are traditionally utilized in acute care and subacute care settings but can also be provided through outpatient and home health care. They are available for adult and pediatric populations and are typically covered by most health insurance providers.[2] Educating patients about these services and how they can be accessed allows them the opportunity to address their rehabilitative needs.

Rehabilitation Services

Physical Therapy

The focus of PT is to strengthen muscles, improve mobility, restore function, and limit functional decline. Patients may seek PT for a wide variety of reasons, such as balance impairment, gait disturbance, range of motion deficits, symptom and pain management, and postsurgical rehabilitation. Interventions focus on bed mobility and transfer training to allow for greater independence and safety at home, gait and balance training to improve ambulation and safety in the community, strengthening programs to address weakness, energy conservation to promote maximal tolerance for activities, manual therapy to lessen connective tissue restriction, and modalities such as ultrasound or electrical stimulation to address pain management. Using these interventions to treat impairments helps patients to regain function and maintain independence throughout their daily lives.

Occupational Therapy

Occupational therapists assist patients in making the most of their abilities to perform their desired activities so that they may live their lives to the fullest. They evaluate the impact of a patient's disability on daily life, ranging from self-care to important roles, and provide interventions that support physical recovery and recovery of cognitive, psychosocial, and general health. Interventions focus on enhancing performance in everyday tasks by strengthening physical abilities, modifying activities and environments, training in the use of assistive devices, and building the skills to overcome symptoms (e.g., cognitive rehabilitation, coping, energy conservation).[5] Occupational therapists help patients break down the activity demands of a valued task and create the right challenges during treatment to facilitate successful performance. Furthermore, they use an evidence- and occupation-based approach in which patients engage in relevant activities to treat their impairments and promote functional recovery.[5]

Speech Language Pathology

SLP provides interventions focused on assessment and treatment of speech, language, cognitive, and swallowing disorders. Speech language pathologists provide essential services to improve QOL and offer treatment that is both curative and preventative across numerous disorders. Therapy addressing communication and cognition may include strategies to improve intelligibility or memory, alternative and augmentative communication devices to improve personal expression, or the use of specialized prosthetics or valves to allow voicing. Swallowing treatment may focus on optimizing oropharyngeal strength and function through exercise or improving oral intake and minimizing aspiration with compensatory strategies (e.g., chin tuck, head rotation) and diet modification (e.g., pureed food, nectar-thick liquid).

Recreation Therapy

RT helps maintain QOL through the use of recreational activity or community-based interventions. By assessing patients' leisure interests and lifestyles, therapists can assist in skill development, knowledge, and behaviors for daily living and community reintegration.[6] They work with patients and their families to incorporate specific interests and community resources into therapy to achieve optimal outcomes that carry over to the patient's daily life.[6] By addressing these factors, the therapeutic process becomes more meaningful and relevant, resulting in improved engagement in therapy and functional improvement for all areas of life.[6]

Palliative Focus

When patients transition to palliative care, rehabilitation therapists apply a fluid treatment approach to properly address the specific needs of this population. Specifically, rehabilitation therapists modify treatment goals throughout the palliative process by providing therapy that may initially focus on reduction of impairment and then transition to care that is centered on comfort and QOL. Physical therapists provide more compassionate care by assisting patients in maintaining their mobility and transitioning to training in adaptive equipment as physical capabilities decline.[7] Occupational therapists present remedial and compensatory strategies to address evolving barriers to participation and find creative ways to foster the best level of independence for meaningful activities.[8] Speech language pathologists provide compensations that transition from minimizing aspiration to those focused on improved comfort and social engagement in the process of eating and drinking.[9] Recreational therapists address patients' abilities to cope with their emotional responses to progressive illness and help patients re-engage in previously enjoyed leisure interests through adaptive methods.

Rehabilitation Interventions

Key Principles in Palliative Rehabilitation

Palliative rehabilitation is guided by the following key principles: communication and collaboration, addressing disability, easing symptom burden, adapting through all stages of illness, and cultivating QOL. Each of these principles guides the therapy process to help a patient achieve his or her palliative goals.

Communication and Collaboration

Communication and collaboration are integral components of creating successful partnerships between patients and therapists. Efforts to foster effective communication require therapists to have a holistic understanding of patients and for patients to be aware of the benefits rehabilitation can provide. During the screening process, the palliative care team educates patients on the range of rehabilitation services available and the types of interventions to address their needs. Nurses play a key role in providing this education and initiating referrals so that patients can understand how rehabilitation applies to their care. Nurses can also share concerns regarding patient safety and needs between therapists and other disciplines.

Palliative rehabilitation is patient-centered, with an emphasis on collaborative goal-setting. Patients and therapists maintain shared decision-making throughout the treatment process by co-creating goals based on what is meaningful and attainable to the patient and taking into account prognosis. Therapists ensure that goals are collaborative by considering patient needs, motivations, and desires. Following these principles enables therapists to address patients' valued tasks, functions, and goals. This allows therapists to build trust and rapport, which then results in patients achieving maximum benefit from the palliative process.

Case Study: Communication and Collaboration

During his clinic visits, JP's nurses recognized the impact his progressive weakness and symptom burden had on his function, and, after educating him about the rehabilitation services available, they agreed to obtain a referral from his oncologist for rehabilitation. In his initial outpatient evaluations, he shared his frustrations regarding the debilitating effects of his condition. He experienced decreased mobility, multiple falls, difficulty managing his home and coaching boxing due to significant fatigue, and challenges in talking and sustaining safe feeding methods. He and his therapists were able to assess his needs and determine the appropriate treatment plans to address his deficits. PT assessed impairments in gait, strength, and balance that were contributing to his falls. OT assessed his routines of home maintenance and coaching and created goals to manage fatigue and adapt the way he performed relevant tasks. SLP addressed his difficulty swallowing and focused on identifying specific postural strategies to improve his airway protection rather than modifying his diet to include thick liquid. His therapists and he developed strong therapeutic relationships built on collaborative goals to support the most independent and meaningful functions.

As he experienced more frequent hospitalizations with the progression of his disease, his therapists provided ongoing inpatient support, creating new goals to prevent further decline while managing symptoms. RT was introduced into his care to support his goals of maintaining leisure engagement and coping through his prolonged hospitalizations. While he had hoped to recover to his baseline during his final admission (e.g., walking and eating normally), he understood this was infeasible; however, his therapists helped him preserve his sense of identity and QOL as much as he could toward the end of life.

Addressing Disability

Palliative rehabilitation helps patients address the disability that occurs as an illness advances so that they can maintain optimal function and physical health. Therapists design treatment plans to minimize decline in function by remediating deficits when appropriate or compensating abilities when losses become permanent. Their efforts focus on preventing the impact of disability throughout all stages of care, so that patients can continue to function in their desired manner while reducing caregiver burden.

Physical Activity

Engagement in physical activity can help patients address loss of physical abilities at any stage of disease. Physical therapists address these issues through exercise programs, gait and balance training, activity modifications, and provision of appropriate durable medical equipment (DME) (e.g., walkers, wheelchairs, lifts, etc.). Physical interventions that focus on maximizing/maintaining physical abilities and mobility can prevent the progression of weakness, allowing patients to remain physically active in their environments. Patients receiving palliative care who engage in structured physical activity can improve their functional levels, satisfaction with their abilities, and QOL, as well as improve their likelihood to discharge home as opposed to a facility.[7] These programs also offer multi-aspect interventions that are tailored to each patient and his or her specific needs, such as a patient's particular levels in strength, endurance, balance, posture, and joint health.[10,11] Patients who engage in these types of programs, such as routines consisting of warm-up, circuit/strength training, balance exercises, and cool-down, can demonstrate improvements in their physical abilities compared to remaining sedentary.[10,11]

Function and Engagement

Activities of Daily Living

Occupational therapists help patients retain their self-care abilities and performance for basic activities of daily living (ADLs) such as dressing, grooming, bathing, personal device care, and sexual activity. Patients learn strategies such as modified physical techniques to transfer to a toilet or incorporate proper body mechanics during a shower, which are important in enhancing independence and ensuring safety. Occupational therapists provide recommendations and training in adaptive equipment, such as how to use a universal cuff to compensate for loss of hand grasp when trying to handle utensils during feeding or how to utilize magnifying tools to assist with applying makeup when vision declines. They also help patients perform self-care routines in an efficient manner by integrating energy conservation principles to minimize pain or fatigue during the process. These strategies help patients preserve a greater degree of functional independence for ADLs in their personal routines, thus improving satisfaction in their abilities.[12]

Instrumental Activities of Daily Living

Occupational therapists assist patients in performing instrumental ADLs (IADLs), such as meal preparation, financial and home management, caregiving, or spiritual activities. They help patients problem-solve these activities, finding creative ways to modify tasks into more manageable processes and to reinforce the use of energy conservation and assistive devices.[8] Recommendations for environmental modifications also help patients interact in their environments in a safer and more convenient way, such as recommending where to appropriately install handrails or grab bars to enhance safety or reorganizing kitchen spaces by consistently placing objects within a reachable area to improve ease of accessibility.

Communication Management

Speech language pathologists provide communication intervention to improve active participation in communication areas such as socialization, decision-making, and expression of needs. They perform speech, language, and cognitive evaluations to identify a patient's communication strengths and weaknesses. Specific interventions vary greatly but may include low-tech augmentative and alternative communication tools such as simple letter boards, use of speaking valves with tracheostomized patients, or communication strategies such as simple "yes" or "no" questions for patients with fair auditory comprehension but poor expressive ability. Optimizing communication and providing education to family and other care providers is crucial for improving active participation in patient- and family-centered and interdisciplinary goal discussions.

Leisure Education

Recreation therapists help patients develop the awareness, knowledge, and skills needed to facilitate active leisure engagement when disability deprives them of their usual habits. They provide leisure education, which focuses on patients' individual capabilities and emphasizes their strengths and interests, so that they may competently participate in activities of their own choosing. Recreation therapists collaborate with patients to modify recreational activities they enjoy (e.g., manipulating the weight of a basketball or lowering the height of the hoop) and match challenges to their current abilities to promote self-esteem. Obtaining this balance creates an inclusive leisure experience that results in patients' feeling a greater level of self-fulfillment and achievement of potential.[13]

Supporting Caregivers

While maintaining patient function can reduce caregiver burden, therapists also help caregivers improve their abilities to support patients. Occupational and physical therapists instruct caregivers on how to perform safe transfers, as well as how to manage DME and assistive devices to better assist patients. Speech language pathologists instruct caregivers on proper feeding strategies and also provide education and support to assist in difficult decisions regarding eating and drinking, including the use of feeding tubes. Recreation therapists educate caregivers on the value of leisure engagement and recommend activity adaptations that can assist in planning recreational experiences. By improving caregiver competency in assisting patients, they can decrease feelings of helplessness and focus their efforts in productive ways. These efforts benefit patients who desire to remain in their homes and their families who wish to keep them there.

Physical Complications

Joint Integrity

To address the risk of contractures that may occur as a result of prolonged immobility, therapists can help patients maintain, maximize, or increase range of motion. Physical therapists address joint integrity through stretching programs and soft tissue and joint mobilization, each of which promotes mobility and alleviation of pain. For patients who experience innervation or pain-related issues (e.g., drop foot, plantar fasciitis, or overpronation), physical therapists can recommend and fit patients with lower extremity orthotics to support the affected joint and increase functional mobility. Similarly, occupational therapists can recommend splints for upper extremity contractures to improve function and comfort and prevent further deformity.

Skin Integrity

Therapists also contribute to efforts to reduce the risk of developing pressure ulcers. Therapists help patients become more independent in repositioning strategies and compliant with proper body mechanics to avoid conditions that increase pressure on skin areas. They also recommend appropriate assistive devices used to decrease skin breakdown during activities, such as cushions on seating surfaces. Participating in therapy provides patients the opportunity to perform out-of-bed activities and prevents prolonged periods of lying or sitting.

Dysphagia

Dysphagia can lead to pneumonia, weight loss, and poor nutrition; however, speech language pathologists provide recommendations and education to reduce these complications. Dysphagia interventions aim to improve swallow efficiency and safety, which may often include weighing the benefits and risks of choosing oral intake versus non-oral nutrition/hydration. The goal of feeding tubes may be directed toward assisting in nutritional status and weight gain; however, research suggests that non-oral nutrition does not decrease the risk of aspiration-related illness or improve QOL or longevity.[14,15] Patients receiving palliative care may choose to eat and drink regardless of aspiration risk, as this may significantly improve QOL. For these patients, speech language pathologists can offer education and training to minimize the risk of developing aspiration-related illness. As end of life nears, speech language pathologists also provide education and family support for thirst and hunger as it relates to patient comfort.

Case Study: Addressing Disability

JP's therapists provided specialized interventions to address his deficits so that he could function in a more capable manner. During his outpatient visits, PT provided JP therapeutic exercises on gait, strengthening, and balance to slow the progression of his weakness and maintain mobility and safety in his home and community. OT taught him to analyze and optimize the process of keeping his front yard within Homeowners Association standards by simplifying gardening tasks through training in adaptive tools, such as using a tractor scoot or long-handled weed cutter, to improve ergonomics. OT also suggested he modify his yard space by keeping his lawn at an even level to avoid potential falls. SLP referred him to an otolaryngologist, where he received a vocal cord injection which improved both his voice and swallowing, allowing him to safely eat and drink without restriction. In addition, SLP helped maintain and optimize his swallow function with exercise.

During JP's final admission, the progression of his disease threatened his function even further; however, his therapists bolstered their approach of maintaining his functional capacities. Through RT groups, JP was able to develop new leisure habits as he discovered recreational activities that accommodated for his deficits, such as wheelchair bocce ball, which provided ongoing opportunity to experience the competitive challenges that he enjoyed from physical sports. As a result, he gained more confidence, which motivated him to put in greater effort to interact with other patients and engage in therapy. As his lower extremity weakness escalated to paralysis, PT focused on maximizing his core strengthening and training in proper body mechanics to perform safe slide board transfers into a wheelchair. OT helped him incorporate those transfers into his ADLs, enabling him to continue to shower with minimal assistance and shave his head independently in an upright position so that he could maintain a positive image of himself. SLP assisted in communication strategies to improve his voice and respiratory speech coordination, as his ability to communicate was complicated by his respiratory status.

JP's therapists also helped prevent potential complications as he became increasingly bed-bound from worsening paralysis. He and his therapists developed daily routines of out-of-bed activity and repositioning to prevent pressure ulcers and muscle atrophy. PT fitted him with ankle-foot orthotics to keep his feet in a functional position, while OT provided the appropriate wheelchair cushion to prevent skin breakdown. As his swallowing continued to decline, JP struggled with recurrent pneumonia and weight loss and eventually required a feeding tube to meet his nutritional needs; however, SLP provided therapeutic feeding strategies so he could continue to take small amounts of his favorite foods, which allowed him a familiar comfort. These preventative efforts curbed the rate of deterioration he could have experienced.

Easing Symptom Burden

The rehabilitation team collaborates with the palliative care team to assist in symptom management, and they have unique abilities to address debilitating symptoms that impact daily function. Therapists provide interventions to improve or reduce the experience of patients' symptoms, allowing them to manage their disease more effectively and engage in daily life with more comfort.

Fatigue

Use of fatigue management strategies can complement physical activity interventions and compensate when exercise by itself is not sufficient. Occupational therapists help patients analyze their daily routines and understand how their habits, sleep, and nutrition factor into fatigue levels. They teach patients how to develop healthier habits by planning and prioritizing their activities, organizing routines based on energy levels, and breaking up tasks into manageable parts.[16] Physical therapists instruct patients on proper body mechanics, paced breathing, and activity modification to decrease physical exertion. They also grade exercise programs to match the necessary cardiovascular endurance and strength needed for optimal activity tolerance.

Pain

Therapists support interdisciplinary efforts to manage pain, providing interventions that complement their pharmacological regimens. Occupational therapists help patients understand the physiological effects of pain and teach them how to use relaxation strategies to cope with and decrease the intensity to pain.[16] Occupational therapists also teach patients to assess pain in their lifestyle, determining how behaviors trigger or exacerbate pain, which results in learning how to decrease the impact of pain on function.[17] Physical therapists help patients utilize muscle and nerve stretching, soft tissue mobilization, positioning, and posture training, all of which reduce pain in mobility and extremity range of motion during functional activities. Engaging in leisure activities facilitated by a recreation therapist may also offer patients a positive distraction that decreases their overall pain experience.[18]

Cognition

Cognitive dysfunction results from the deterioration that occurs with neurodegenerative brain disorders, as well as from the culminating effects of fatigue, anxiety, stress, and medication.[1,16] Both occupational therapists and speech language pathologists play a role in addressing cognitive skills related to attention, memory, and executive function, with each discipline focusing on its respective scopes of practice as occupational therapists address ADL and IADL function and speech language pathologists address communication. They provide attention/memory training, compensatory strategies (e.g., planners, assistive technology, etc.), and activity-related problem-solving focused on modifying component tasks to decrease cognitive burden and facilitate participation. Exercise is another tool therapists can use to address cognitive function in patients because consistent physical exercise over time can improve or maintain higher levels of executive function compared to those who are inactive.[19] Participation in RT groups that provide cognitive stimulation, such as socialization and multisensory leisure for patients with Alzheimer's disease, can improve language and memory function.[20]

Dysphagia

Traditionally, speech language pathologists provide dysphagia intervention focused on eliminating aspiration with feeding; however, this goal is often not appropriate for certain patient populations. For patients with dysphagia receiving palliation, the goal should shift to minimizing distressing symptoms related to swallowing, such as cough or dyspnea with eating. This may be accomplished with the use of compensations such as modifying diet textures, feeding rates, bolus size, or the positions in which patients eat and drink. The goal is to offer treatment that is least restrictive, which may redirect the focus on compensatory strategies over diet modification. Certain diet modifications, such as thick liquids, may not reduce the occurrence of aspiration-related illness but may increase the risk of dehydration and negatively impact QOL with eating or drinking.[21]

Dyspnea

As certain conditions lead to decline in pulmonary function, therapists can assist patients in managing dyspnea and the associated symptoms of breathlessness, poor activity tolerance, and anxiety. Patients may maladaptively respond by avoiding activity, leading to further disability and disengagement from daily life.[22] To treat these effects, occupational therapists and physical therapists provide pulmonary rehabilitation through physical conditioning to promote efficient oxygen utilization of the body and maximize activity tolerance. Occupational therapists, physical therapists, and speech language pathologists also provide respiratory retraining to improve oxygen saturation and minimize reliance on supplemental oxygen. These efforts maximize pulmonary function, helping patients breathe properly and comfortably during their activities.

Mood

To manage the psychological effects of living with progressive illness, therapists can assist patients in coping with anxiety, depression, and other emotional symptoms that affect mood. Occupational therapists help patients develop individualized coping plans by helping them practice the skills of deep breathing, meditation, progressive muscle relaxation, and guided imagery to decrease overall physiological and psychological stress.[16] Exercise can have positive effects on anxiety and depression by improving the neurobiological mechanisms of the brain, allowing the body to better regulate mood compared to the standard treatment alone (e.g., medication or psychotherapy).[23,24] When patients experience feelings of fear, helplessness, and loneliness, recreation therapists engage them in group treatments to minimize social isolation through the provision of positive peer interactions.[18] They may also provide animal-assisted therapy to alleviate stress and anxiety, allowing patients to feel a greater sense of comfort in the hospital.[18,25]

Case Study: Easing Symptom Burden

JP and his therapists worked together to alleviate the symptoms he experienced from cancer and cancer treatment. To overcome his persistent fatigue, PT graded his endurance program and encouraged maintenance of proper form throughout different physical activities to reduce overexertion. OT helped JP understand his daily fatigue patterns and spread his tasks out appropriately, with restful breaks to use his energy efficiently. To better manage his dyspnea, he was trained in incentive spirometry and pursed-lipped and diaphragmatic breathing, allowing him to minimize his oxygen requirement and decrease his anxiety associated with breathlessness. To manage his spinal pain, JP learned how to avoid pain-triggering positions and to incorporate progressive muscle relaxation to improve his tolerance for upright activities. To address dysphagia, SLP provided additional swallowing strategies to minimize cough and discomfort with eating. To cope with feelings of depression, recreation therapists engaged JP in journaling as a way of creative self-expression, providing a positive outlet while OT helped JP utilize guided meditation to redirect his focus toward calming behaviors.

Adapting through All Stages of Illness

Palliative rehabilitation takes into account the challenges of providing care when patients experience irreversible changes, prompting therapists to continually monitor and assess how fluctuations in function and increasing symptoms can create conditions for despondency. Beyond the previously noted interventions, therapists concern themselves with understanding that patients' lives will never be the same as identities are damaged by disability; however, changing the disability narrative can facilitate adaptation and help redefine identity. For example, speech language pathologists help patients cope with and accept the new normal of being dependent on tube feeds or speaking valves. Physical therapists empower patients to use their bodies in new ways to master how they interact within their environments. Occupational therapists can coach patients on how to redesign their lifestyles by establishing new behaviors and routines that maintain the essence of identity-based activities and improve motivation to manage their health.[26] To guard patients' self-esteem against the threats of progressive disability on their confidence, recreation therapists facilitate success in strengths-based leisure activities, promoting a sense of accomplishment.

Group therapy can provide adaptive experiences that support psychosocial adjustment and address the effects of prolonged hospitalizations that impact the sense of normalcy, enjoyment, and social connectivity patients would otherwise have in their normal environments. For example, recreation therapists facilitate recreational and social group treatment sessions to provide patients the opportunity to re-experience feelings of pleasure, voice their emotions, and improve comfort, all of which help them adapt in unfamiliar environments. By experiencing therapeutic leisure activity with others facing similar difficulties, patients can decrease the risk of social isolation and gain psychological support and empathetic understanding from their peers.[18]

Case Study: Adapting through All Stages of Illness

One of the most meaningful ways that JP's therapists helped him adapt was helping him redefine his role as a boxing coach. JP was accustomed to coaching his pupils in a hands-on style by physically joining them in the ring. As he could no longer confidently coach in this manner, PT helped JP develop new strategies with balance and kinesthetic awareness, allowing him to adapt his footwork and safely participate in sparring. OT adapted his daily schedule, finding an optimal way of organizing his time throughout the week to maximize energy during his lessons. He also learned a new coaching routine of substituting his pupils in his place or showing prerecorded portions of his lessons to balance teaching and conserving energy. These efforts helped him continue to coach in a satisfying manner and experience the gratification of mentoring his pupils.

During his final admission, RT helped JP adjust to his prolonged hospital experience. By routinely participating in recreation groups, he overcame his initial social isolation by developing friendships with those who also struggled with the challenges of cancer, giving him a sense of camaraderie that motivated him to remain committed to keeping a positive attitude. When he became paralyzed, RT introduced new board games he could play in bed, which provided him with an enjoyable activity that he shared with his family. The success he had in these games functioned as a way to continue to exercise his mental strengths and helped him acknowledge he was still capable of planning pleasant, enjoyable experiences with his family.

Cultivating QOL

The ultimate goal of palliative rehabilitation is to improve or preserve QOL. Outcomes of care are not only based on achievements in function, but also on how patients perceive a greater level of satisfaction and well-being within their remaining time. By addressing physical dysfunction and management of symptoms through exercise, physical therapists can help patients experience achievement, confidence, self-empowerment, and group camaraderie, resulting in perceived improvement in their QOL.[27] Occupational therapists help patients to maintain their best level of independence in their self-care and participation in meaningful life activities despite their deficits, protecting their sense of autonomy, productivity, and dignity. Speech language pathologists help patients' optimize their ability to communicate, so they can express needs and engage socially, which improves emotional and spiritual well-being. Speech language pathologists also provide families with rewarding experiences when patients can comfortably share a meal. As recreation therapists facilitate leisure engagement and group activities, patients gain an outlet in which they can express emotions, display creativity, and enhance a sense of control and self-esteem through the accomplishment of task-oriented goals.[18] The intangible benefits that result from these collective efforts contribute toward QOL and assist in allowing the true benefits of palliative care to be actualized.

Palliative rehabilitation also addresses QOL as it relates to mortality. Therapists help patients alter their experience of a terminal disease by ameliorating the effects these circumstances have on QOL. They help patients direct their efforts toward positive activities, such as legacy-building or improving the manner in which time is spent alone or with family. Therapists can also help patients and their caregivers prepare for their transition to hospice, providing guidance for how to plan their remaining time in a meaningful way and addressing any further needs for training or equipment.

Case Study: Cultivating QOL

Each interaction JP shared with his therapists functioned as a way of improving his QOL. Because of his care, he was able to continue to transfer and maintain an upright position in a chair, groom himself to keep his desired features, share meal experiences with his family, and form new social networks with which to share enjoyable moments, all of which allowed him and his family to cultivate quality moments that brought value to his palliative experience. When JP decided to transition to home hospice, his therapists helped him focus on his family even further by working together on a legacy project of compiling his barbecue recipes so that his family could remember him during their holiday gatherings after he passed. Despite the losses JP experienced toward the end of his life, the rehabilitation team was able to help him maintain a sense of comfort, autonomy, and accomplishment that helped him cope through the full spectrum of his experiences.

Conclusion

Palliative rehabilitation plays a vital role within the palliative care team by providing interventions that address various needs to support maximal function and management of symptoms. Including rehabilitation as part of the palliative care plan adds supportive elements that improve interdisciplinary collaboration, moderate the impact of disability and symptom burden on daily life, and, ultimately, support QOL through every stage of disease. Nurses work closely with therapists to screen and refer patients who can benefit from palliative rehabilitation and maintain effective communication of the needs and concerns of patients and their families. Together, nursing and rehabilitation can help to alleviate patient and caregiver suffering to ensure patients have the best possible outcomes by collaborating as a team.

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CHAPTER 57

Value-Based Care

Finly Zachariah and William Dale

Key Points

- Aligning patient preferences with care delivery is fundamental to providing value-based care.
- Nurses are integral to the care team and have several opportunities to impact care delivery.
- Palliative medicine is well-positioned to substantially impact rising, unsustainable healthcare costs.

Introduction

Value-based care is defined as evidence-based care that helps patients improve their health, reduce the effects from chronic diseases, and live healthier lives.[1] This is in contrast to a fee-for-service (FFS) model, in which greater volumes of care lead to higher payments independent of outcomes. Translating this philosophical approach into effective programs is the new challenge for healthcare systems. Value-based programs offer providers incentive payments based on providing quality of care.[2] Value-based programs support a three-part goal to provide (1) better care for individuals, (2) better health for identified populations, and (3) lower costs of care.

In the United States, healthcare expenditures continue to grow at an unsustainable rate, with $ 3.3 trillion (17.9% of gross domestic product [GDP]) spent in 2016.[3] The FFS model, paying for the volume of service whether appropriate or not, has been a major driver of higher healthcare expenditures in the United States.[4] There has been a concerted effort in healthcare reform to shift payments from being centered on volume to instead paying for value.[5,6] The concept of "value" originates from the Latin word *valeir,* to "be worth," and is defined by Merriam-Webster Dictionary as the "monetary worth of something."[7] Michael Porter in the *New England Journal of Medicine* stated "achieving high value for patients must become the overarching goal of healthcare delivery, with value defined as the health outcomes achieved per dollar spent."[8] With healthcare now involving many parties, most importantly the patient and his or her family, the interdisciplinary healthcare team, the patient's community, policymakers, and insurance agencies, important questions to now ask are: (1) What are meaningful, measurable outcomes? And (2) What are the best outcomes for patients and families that can be achieved with the healthcare dollars being spent?

Depending on the interested party, outcomes of importance may shift. For the payer, the most important outcome may be what provides similar outcomes at the lowest financial cost. For the provider, it may be improving overall survival or achieving disease-based outcome targets, such as a specific level of hemoglobin A1C for patients with diabetes. Policymakers may be most concerned with providing consistent care and minimizing variance in outcomes at a population level, and for patients, their most desired outcome may be overall survival, maintaining a high quality of life, maximizing functionality, and minimizing symptoms. Keeping these different perspectives in mind and trying to reconcile them are crucial to a value-based approach.

In 2012, the California Healthcare Foundation conducted a study on Californian's Attitudes and Experiences with Death and Dying, which provides information on understanding important outcomes to patients nearing the end of life. Key findings included:

- Two-thirds of Californians state that the most important factors at the end of life were (1) being comfortable and without pain and (2) assuring their families were not burdened by the financial costs of their healthcare.
- Sixty percent felt it was "extremely important" that families not be burdened by tough decisions about care, although 56% of Californians did not communicate healthcare wishes to their healthcare agents.
- Eighty-two percent said it was important to have written end-of-life (EOL) wishes, but only 23% say they have written those wishes down.
- Seventy percent stated they would prefer to die at home, but, in fact, only 32% of deaths occurred at home, while 42% were in a hospital and 18% were in a nursing home.
- Eighty percent said they would like to talk with their doctors about EOL care, but only 7% of those surveyed had a doctor speak to them about EOL care.[9]

Physicians approach their own care at the end of life with better preparation, but still do not communicate their preferences well with their own physicians. The Precursors Study enrolled 999 physicians when they were medical students attending Johns Hopkins School of Medicine from 1948 to 1964. The ongoing annual surveys revealed that although 64% had an advance directive that was discussed with spouse or family, 70% had not had a conversation with their personal physicians about EOL care. Additionally, 80% of the physicians indicated they would want pain medications and 85% would refuse life-sustaining treatment at the end of life.[10] Two other studies, one in Singapore, indicated a strong physician preference against life-sustaining treatments at the end of life.[11,12] Another study in the United States compared EOL care utilization between physician (9,947) and nonphysician (192,006) fee-for-service Medicare beneficiaries. Inpatient hospitalization was similar between the groups, but intensive care unit

(ICU) utilization and number of days in hospice was higher for the physician group.[13]

The 2014 report by the Institutes of Medicine, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, further expounded on the inadequacy of the EOL care provided by our current healthcare system. Some of the key findings included:

- Palliative care is associated with improved quality and quantity of life, improved understanding and communication, and bio-psycho-socio-spiritual (physical, emotional, social, and spiritual needs) care.
- Healthcare delivery is fragmented due to transitions and preventable admissions fueled by misaligned incentives.
- Communication with patients regarding values, goals, and preferences is lacking and timely palliative care involvement is not well-adopted.
- Advance care planning conversations are necessary, but most patients do not have them with their healthcare team.
- Training and reimbursement are inadequate for providers wanting to utilize palliative skills.
- There is a need for increased public awareness and a societal conversation around care at the end of life.[14]

The *Dying in America* report also had five key recommendations, and these provide the framework for this chapter, which explores the significant palliative care opportunities for nurses to improve the care of seriously ill and dying patients. There are opportunities for all nurses through the dissemination and adoption of primary palliative care skills, while those with more experience and certification are able to provide specialty-level palliative care.[15] The field of palliative care is dedicated to bio-psycho-socio-spiritual care and treatment of seriously ill patients and their families. This care, delivered by an interdisciplinary team, has been recognized by the World Health Organization as a human right and is included in major guideline recommendations.[16–19]

Recommendation 1: Delivery of Person-Centered, Family-Oriented End-of-Life Care

> Ideally, healthcare should harmonize with social, psychological, and spiritual support to achieve the highest possible quality of life for people of all ages with serious illnesses or injuries. Toward this end, the IOM committee recommends that integrated, person-centered, family-oriented, and consistently accessible care near the end of life be provided by healthcare delivery organizations and covered by government and private health insurers. The committee finds that a palliative approach typically affords patients and families the highest quality of life for the most time possible. . . . Although palliative care is well established in most large hospitals and professional education programs, the committee identifies the need for greater understanding of the role of palliative care—by both the public and care professionals—as one of the greatest remaining challenges in the delivery of high-quality end-of-life care.[14]

Nurses are integral to the process of care delivery across settings and have had an increasingly important leadership role in the delivery of palliative care. In improving care for the seriously ill and those at the end of life, there are several actions nurses can engage in, including improved communication and advocacy with interdisciplinary staff, optimal physical care, demonstrating care and compassion, supporting dignity and providing emotional support in death for patients and their families, and fostering a peaceful environment.[20]

The lack of qualified professionals in palliative care and concerns over staffing costs have in part led to the exploration of innovative, nurse-led models of care. The nurse is a key member of the interdisciplinary team, and, today, nurses have access to new models of care and new palliative care initiatives.[21] Nurse-led palliative interventions have been applied to a variety of clinical, supportive, and care coordination efforts including establishing survivorship clinics[22] and facilitating navigation in rural clinics,[23] and, in England, a collaborative social work and nurse clinic model has been developed to focus on meeting caregiver needs, answering questions around financial concerns, and addressing concerns related to caregivers' health and supporting ill loved ones.[24] In the CONNECT trial, nurses have also been able to provide palliative care in oncology clinics, focusing on symptom management, engaging patients and families in advance care planning, providing emotional support, and coordinating care.[25] There has been evidence of the effect of nurse-led interventions on decreasing admissions and readmission, length of stay, and healthcare costs, although further studies are necessary to understand whether the cost savings generated are sufficient to justify replication of these care models.[26]

Recommendation 2: Clinician–Patient Communication and Advance Care Planning

> Many people nearing the end of life may not be physically or mentally capable of making their own care decisions. In addition, family members and clinicians may not be able to accurately guess what a person's care preferences may be. Therefore, advance care planning is critically important to ensure that patients' goals and needs are met. Although advance directive documents can be useful, they should allow healthcare agents and care providers to make informed decisions in certain circumstances and should not take the place of open, continuous communication. According to the IOM committee, the advance care planning process can begin at any age or state of health and should center on frequent conversations with family members and care providers. Electronic storage of advance directives, statements of wishes, or other relevant materials holds promise for improving access to and effectiveness of these materials. Professional societies and other organizations that establish quality standards should develop standards for clinician–patient communication and advance care planning. Payers and healthcare delivery organizations should adopt these standards as a necessary component of high-quality care for individuals with advanced serious illness and their families and enable them to seek these services from their physicians and providers.[14]

Advance care planning was recently defined by an international panel of experts as "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive care that is consistent with their values, goals and preferences during serious and chronic illness."[27] Where advance care planning is a process and a conversation among patient, medical team, and healthcare agents, there are also some defined products of advance care planning conversations, such as advance directives and life-sustaining treatment forms, including the physician orders for life-sustaining treatment (POLST).

An *advance directive* comprises typically two components: the *durable power of attorney* and the *living will*. The durable power of attorney indicates who one trusts to speak to the medical team on one's behalf if one is unable to or if one chooses to empower the healthcare agent immediately upon executing the document. The living will component of an advance directive indicates the preferences one has for health and includes treatments one would and would not want. One important note is that advance directives are directives for the future and are instructions to a healthcare agent to execute. These are not immediately actionable, and they require additional forms such as the POLST, medical orders for life-sustaining treatment (MOLST), medical orders for scope of treatment (MOST), physician orders for scope of treatment (POST), or more traditional out-of-hospital do-not-resuscitate (DNR) forms. These forms allow patients to indicate their preferences for resuscitation or allowing natural death, and the majority of these forms allow patients to indicate the level of treatment they may want along with preferences toward medically administered nutrition. Unlike advance directives, forms like POLST can be honored by emergency medical services.

Despite the numerous interventions to increase the rates of advance directive completion, in a review of 150 studies evaluating 795,909 patients from 2011 to 2016, only 36.7% of patients had any type of advance directive.[28] POLST forms are also underutilized.[29] A challenge is that many terminally ill patients, if not connected with palliative care or hospice, too often engage with the medical establishment and often come to the emergency room or hospital for EOL care. In the care of most of the 700,000 elderly patients who die in the hospital annually, most providers will have only known these patients for less than a week, and there is evidence that providers who engage in more serious conversations with patients, after having known the patient for only a short period of time, are perceived as having less empathy.[30–32]

These issues speak to the need to move advance care planning conversations to earlier in the course of care, ideally initiated by primary care providers and nurses who often have long-standing relationships with the patient and family. It is the long-term providers who should initiate these conversations since patients and families expect these conversations with those whom they have a relationship.[33] There has also been some demonstrable successes in advance care planning initiatives, including normalizing advance care planning and advance directive completion for a county,[34] targeting efforts to increase advance directives on file for patients undergoing transplant,[35] and utilizing a web-based advance care planning program that statistically increased advance directive completion and is potentially a scalable advance care planning solution.[36] There is some evidence to suggest that healthcare providers who have their own advance directives are more comfortable communicating with patients about them.[37,38] The use of structured communication tools also assists with the discussion and completion of advance directives.[39] Nurses should engage in advance care planning for themselves and their families to demystify the subject and so that they are further empowered to engage in such conversations to support patient values and clarify medical recommendations.

Recommendation 3: Professional Education and Development

> The education of health professionals who provide care to patients at the end of life has substantially improved in recent decades. Hospice and palliative care is now an established medical specialty, and palliative care has a strong presence in clinical education, professional organizations, and research communities. However, the IOM committee finds that important deficiencies persist. First, recent knowledge gains have not necessarily translated to improved patient care. Second, the supply of palliative care and hospice specialists is small, meaning that many patients must rely on other clinicians who provide care for individuals with serious advanced illness but who may lack training and experience necessary to meet their patients' palliative care needs. The committee recommends that educational institutions, professional societies, accrediting organizations, certifying bodies, healthcare delivery organizations, and medical centers take measures to both increase the number of palliative care specialists and expand the knowledge base for all clinicians.[14]

There is a substantial need for primary palliative skills to be integrated into the general nursing profession, which numbers nearly 3 million in the United States. The palliative care education provided in nurse practitioner and undergraduate nursing programs is inadequate. The deans of 101 nurse practitioner programs were surveyed, and, of their schools, the majority had no more than a few hours of class time and a third provided no exposure to palliative care at all.[40] The American Association of Colleges of Nursing in 2016 put forward new guidelines, Competencies and Recommendations for Educating Undergraduate Nursing Students (CARES), to prepare nurses to care for the seriously ill and their families. These guidelines have 17 components. An online curriculum based on the End-of-Life Nursing Education Consortium (ELNEC) was developed in response to prepare future generations of nurses. In addition, there has also been recent funding for advance practice oncology nurses to be trained with general palliative care skills.[41,42] ELNEC started in February of 2000 and was designed to improve palliative care in the United States and internationally. As of 2018, more than 23,880 attendees have been educated from 99 countries, with these learners taking content back to their healthcare centers and teaching others—more than 670,000 additional healthcare professionals—vital palliative care nursing skills.[43]

Education in palliative care for nurses has been shown to improve knowledge, confidence, attitudes, and communication abilities, as well as to decrease nurses' stress.[44] Targeted palliative education has also been successful in areas like the ICU, after which nurses were able to identify and advocate for alleviation of palliative needs in their patients.[45,46] In the actively dying, a mnemonic that facilitates the role of nurses in EOL care is CARES: *C*omfort, *A*irway, *R*estlessness and delirium, *E*motional and spiritual support, and *S*elf-care. Use of such a mnemonic provides a structured way to assure that patients and their families receive appropriate care in an otherwise stressful situation for patients, families, and staff.[47] Utilizing the TEAM approach, primary palliative principles can be disseminated to the oncology care team to honor the newly revised American Society of Clinical Oncology (ASCO) guidelines, which now incorporate palliative care. TEAM is a mnemonic for *T*ime (an hour per month with the palliative care team), *E*ducation (especially regarding prognosis, goals of care, and advance care planning), *A*ssessments (for symptoms, spiritual, and psychosocial health), and *M*anagement by an interdisciplinary team.[48]

Recommendation 4: Policies and Payment Systems

> Sustainable improvements in the organization and financing of end-of-life care must take into account the need to stabilize

> healthcare costs over time. The IOM committee finds that reform is needed in how resources for care provided near the end of life are organized.
>
> Current financial incentives encourage a reliance on acute care settings that often are costly and poorly suited to the needs, goals, and preferences of patients and their families. The committee recommends a major reorientation of payment systems to incentivize the integration of medical and social services, the coordination of care across multiple care settings, and the use of advance care planning and shared decision-making to better align the services patients receive with their care goals and preferences. This reorientation will improve access to services that better respond to the needs of patients and their loved ones and may also help stabilize healthcare costs.[14]

In a poignant article, Drs. Schenker and Arnold discuss the traditional model of palliative care as much more "proof of concept," and state that the rapidly expanding needs and limited workforce call for a different approach for the future of palliative care. They express: "The next era of palliative care must embrace a broader focus on systems of care, measurement and accountability for palliative services, and national policy changes that promote universal provision of high-quality advanced illness care. Without these changes, it will not be possible to achieve the goal of improving the experience of patients with serious illness."[49]

Estimates for high-income countries indicate that 69–82% of those who die will need palliative care, with increased needs expected due to the aging population, occasionally termed the "Silver Tsunami."[50,51] Studies have previously indicated that the sickest 5% of the population accounts for nearly half of the Center for Medicare and Medicaid services spending. Eleven percent of this population are in their last year of life, but nearly half have expensive procedures. In addition to this 11%, the remaining 40% are also a demonstrated opportunity for palliative care to improve the care of these patients who are often older, have multiple comorbidities (including possibly cognitive impairment), have generally significant functional dependency, suffer from pain and depression, and have the social and financial familial burden of caregiving, along with recurrent emergency room and hospital visits.[52,53] In various settings across a number of life-limiting illnesses, palliative care is fundamentally value-based care and has been shown to improve alignment of a patient's values, goals, and preferences with the care received by patient and family, which often has the secondary consequence of improved quality and quantity of life, decreased utilization, and overall decreased costs to the healthcare system.[54–61]

While hospice is well-defined and structured with appropriate regulatory requirements, the delivery of palliative care faces significant challenges. Palliative care is able to be delivered in the hospital, but otherwise has inconsistent reimbursement by insurance and is generally unavailable at home, in nursing homes, or in rural locations.[53] Ultimately, additional bipartisan support is needed to advance quality initiatives such as the Palliative Care and Hospice Education and Training Act.[53] Reimbursement by Medicare for advance care planning with CPT codes 99497 and 99498 can be utilized by physicians and healthcare providers, including advance practice nurses and clinical nurse specialists (if legally authorized to provide services in their state). In addition, other providers such as nurses may bill under "incident to" in office or home settings, as long as there is another authorized visit performed on the same day.[62]

Recommendation 5: Public Education and Engagement

> The IOM committee identifies a need for public education and engagement about end-of-life care planning at several levels:
>
> - the societal level, to build support for public and institutional policies that ensure high-quality, sustainable care;
> - the community and family levels, to raise awareness and elevate expectations about care options, the needs of caregivers, and the hallmarks of high-quality care; and
> - the individual level, to motivate and facilitate advance care planning and meaningful conversations with family members and caregivers.
>
> Although Americans' values and opinions about end-of-life care will necessarily differ, the committee emphasizes the importance of disseminating accurate information so that individual care decisions and public dialogue, as much as possible, are based on an informed understanding of facts.[14]

Both the American Medical Association and the National Institutes of Health recommend that medical literature designed for patient consumption should be written at the third- to seventh-grade reading level. A study evaluating articles using common search terms through Google found, in a sample of 100 articles, that none was written at less than a seventh-grade level and that the average was written at a twelfth-grade level, making the majority of this educational material incomprehensible to the public.[63] A public consumer website has been made available through the Center to Advance Palliative Care, and it provides content in web, print, and broadcast media to more effectively educate the public on the differences between hospice and palliative care and to demonstrate the benefits of being connected to palliative care teams.[64]

Another recent educational platform has been Death Cafes, typically 2-hour conversational events, hosted in someone's home to discuss death and dying. More than 1,000 sessions have been held internationally since 2011, when the program first started in Great Britain. Death Cafes were held in joint collaboration between the University of California–San Francisco and Zen Hospice in San Francisco and were found to be effective teaching modalities.[65]

Conclusion

Palliative medicine is the fastest growing specialty in the United States and has been shown to improve quality and quantity of life while minimizing over- and undertreatment when care is aligned with patient values through improved communication. Unfortunately, limited progress in care at the end of life has been made, and the needs will continue to outpace the field's ability to train specialists, including nurse specialists. Through disciplined effort in building out primary palliative care for nonspecialists, continuing to educate the next generation, advocating for favorable policies, building and measuring programs, and ultimately focusing on patient-centric care delivery, we will be able to demonstrate value in our care of the seriously ill and dying patient.

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SECTION VI

Pediatric Palliative Care

CHAPTER 58

Symptom Management in Pediatric Palliative Care

Joan “Jody” Chrastek and Camara van Breemen

Key Points

- Assess the dying child thoroughly, with input from the interdisciplinary team, the family, and the child/young adult, if possible.
- Incorporate both nonpharmacological and pharmacological interventions for symptom management.
- Strive for good communication with the child, family, and other team members.
- Be proactive—anticipate and plan for adverse effects from treatment and/or disease progression and develop algorithms for family members’ use.
- Spiritual and psychosocial issues can affect symptoms and management and must be taken into consideration for the family as a whole.

Introduction

Managing symptoms in dying children is challenging and, if done poorly, can be a source of distress for families and children that healthcare providers may fail to recognize.[1] The child and family may fear the unknown future and worry that increasing symptoms signal disease progression and decline.[2] Therefore, aggressive symptom management must start early in the disease trajectory[3]—on diagnosis of a life-threatening/-limiting condition—and continue in conjunction with curative and/or life-prolonging treatments[4] for as long as needed. Listening to the family’s concerns and providing education and reassurance of attention to symptom management can relieve fears.

Assessment and management of symptoms can be straightforward or complex in pediatrics, as in adults. However, many pediatric palliative patients are nonverbal due to their age or condition, making it difficult to identify the cause of distress. The number of subspecialties required increases the complexity of assessment as well as the consideration that a damaged central nervous system may be the source.[2]

These potentially challenging circumstances highlight the necessity of incorporating the whole family, including siblings, as part of the team.[5] They are most familiar with the child’s reactions and methods of communicating. Ideally, the nurse will develop a trusting relationship with the family while remaining objective in assessing and treating the symptoms. Excellent symptom management in children, as in adults, requires the nurse to engage both the art and science of palliative care.

The art of pediatric palliative care is displayed in excellent communication, listening deeply, and understanding what is being asked for or said. Communication is an integral aspect of care,[6] extended to the family and team. Humility, openness, and flexibility are part of a good foundation for this essential aspect of pediatric palliative care.

The science of pediatric palliative care is a rapidly expanding field, with newly developed resources. Using current evidence-based practice provides a strong foundation for optimal symptom management.

When a dying child is distressed, the whole family suffers. Therefore, a holistic approach to all members of “the family” is essential.[7] Siblings’ quality of life (QOL) often suffers in family, academic, and social areas due to a loss of attention and place within the family.[8] Therefore, it is essential that the team consider their well-being in care planning.

Although there is a wide range of underlying conditions in pediatric palliative care, there are common symptoms that will be discussed in this chapter. Each child’s care plan is highly individualized and adjustable. This can be influenced by disease trajectory, culture, beliefs, and their community.

Symptoms arise from physical, emotional, social, and spiritual domains. This chapter focuses on physical symptoms, apart from the pain (described in other chapters), commonly found in children with palliative care needs,[4,9,10] including some respiratory, gastrointestinal, and neurological symptoms.[4,10,11] Emotional and spiritual suffering will be discussed briefly. A resource list is provided (Box 58.1), so that each symptom can be explored in depth.

Assessment

Nurses have a responsibility to assess patients in the context of a developmental, child-specific, and family-centered framework, and this requires competence in communicating, using symptom-specific tools, performing a physical exam, and recognizing specific disease/conditions. There are several tools (e.g., pediatric Memorial Symptom Assessment Scale[12]) that can be used to assess symptom burden in children and each has advantages and disadvantages.[13,14] Assessment for any presenting symptom begins with understanding the history, recent investigations, psychosocial environment, and current medications and treatments. The patient’s developmental stage, verbal ability, and cultural factors

Box 58.1 Useful Websites

1. *The National Paediatric Palliative Care Clinical Network*. The following guidelines have been developed by the National Paediatric Palliative Care Clinical Network with the support of the Ministry of Health of New Zealand and are intended to be used by secondary medical, nursing, and allied health providers who care for babies, children, and young people at the end of life. It is not intended that the guidelines be used by primary care providers or by providers in neonatal intensive units. These guidelines are not suitable for use outside the Palliative Care setting. Visit https://www.starship.org.nz/for-health-professionals/national-paediatric-palliative-care-clinical-guidelines/#All
2. *Together for short lives* (www.togetherforshortlive.org.uk) is a UK-based organization working to improve care and services for children with life-threatening or terminal conditions and their families. They have a list-serve and other resources. A searchable database for literature for the health professional is accessible through www.act.org.uklpageslppI1.asp
3. To look up natural medicines that families may be using, visit the *Therapeutic Research Center*'s Natural Medicines page at https://naturalmedicines.therapeuticresearch.com/
4. *The National Pediatric Hypnosis Training Institute* (http://www.nphti.org/) provides training in ongoing clinical hypnosis skill development for advanced practice pediatric clinicians to assist children and teens in developing self-regulation, optimizing resilience related to medical and mental health issues and stressful experiences, and maximizing well-being and peak performance.
5. The *Hospice and Palliative Nurses Association* (HPNA) is a US-based nursing organization with web-based resources for professionals and families (www.HPNA.org).
6. The *Initiative for Pediatric Palliative Care* (www.ippcweb.org) is a comprehensive website with curricula and resources, including videotapes and other helpful educational resources.
7. The *National Hospice Palliative Care Organization* (www.nhpco.org) hosts the ChiPPS Curriculum, a collaboration between the Children's International Project on Palliative/Hospice Services and the National Hospice and Palliative Care Organization; visit www.nhpco.org/i4a/pages/index.cfm?pageid=3409
8. The *End of Life/Palliative Education Resource Center — Fast-Facts* offers downloadable resources relating to education about end-of-life care (not specific to but includes pediatrics), oriented for physicians and applicable to other health professionals. This resource will now be housed in the American Academy of Hospice and Palliative Medicine (AAHPM) at http://www.aahpm.oral.
9. The *Growth House* (http://www.growthhouse.org/death.html) is an all-round palliative care/grief and bereavement clearinghouse with links for health professionals, families, and volunteers.
10. The *Canadian Virtual Hospice* (www.virtualhospice.ca) is for patients of all ages, their families and friends, healthcare professionals, and healthcare volunteers. It provides information about physical symptoms of illness and deals with some of the emotional reactions and spiritual questions often experienced by patients and their families. The site includes chat rooms, bulletin board discussion areas, and e-mail access to a healthcare professional with expertise in palliative care, as well as resource lists of local hospices and palliative care programs, related products and services, books, a searchable researcher database, website links, and downloadable resources.
11. The *Pediatric-Pain Mailing List* (http://pediatric-pain.ca) is an international Internet forum for informal discussion of any topic related to pain in children.
12. The *Ian Anderson Continuing Education Program in End-of-Life* (www.cme.utoronto.ca/endoflife) is an accredited national continuing education program tailored to the needs of both family physicians and specialists.
13. The *Pediatric Palliative Care Mailing List* (paedpalcare@act.org.uk) is a searchable database for healthcare professional literature.
14. The *City of Hope's Pain/Palliative Care Resource Center Website* (www.citvofhope.org/Pfc/), which Betty Ferrell has been involved in for a number of years, has a large number of online resources for professionals and practitioners.
15. The University of Michigan hosts a series of workshops (http://open.umich.edu/education/med/resources/palliative-care/2010) that provide skills to pediatric physicians, nurses, respiratory therapists, and other health professionals that will improve their ability to care for pediatric patients who are dying in the hospital. They have developed three workshops; each takes about 90 minutes. These workshops feature videos of simulated doctor–patient interactions, worksheets, self-evaluations, and more.
16. The *Music Therapy Organization* (https://www.musictherapy.org/assets/1/7/MT_Young_Children_2006.pdf) website offers a resource to learn more about music therapy for young children.
17. The goal of the *Courageous Parents Network* (https://courageousparentsnetwork.org) is to empower parents caring for children with serious illness through video, shared community, professional guidance, and palliative care.
18. The *Dana Farber Pediatric Pain and Symptom Management Guidelines 2014* (http://pinkbook.dfci.org/assets/docs/blueBook.pdf) booklet is a guide to symptom management in children and a tool for identifying areas for self-study. Pharmacologic options for pain and other distressing symptoms are provided. (Use of medications requires adequate knowledge of side effects and drug–drug interactions. These suggestions cannot replace medical consultation.)

(*continued*)

Box 58.1 Continued

19. The *Canuck Place Children's Hospice, Vancouver, Canada* (www.canuckplace.org) is a caring, innovative children's hospice and community-based service that fully embraces the life of each child and family. They provide leadership in improving pediatric palliative care regionally, nationally, and internationally through collaboration, education, and research.
20. The *National Institute of Nursing Research* (NINR) (https://www.ninr.nih.gov/newsandinformation/conversationsmatter/media) supports and conducts clinical and basic research and research training on health and illness across the lifespan to build the scientific foundation for clinical practice, prevent disease and disability, manage and eliminate symptoms caused by illness, and improve palliative and end-of-life care.
21. The *International Children's Palliative Care Network* (http://www.icpcn.org/) works to raise awareness of children's palliative care, lobbying for the global development of children's palliative care services and sharing expertise, skills, and knowledge.
22. The Palliative Care Network of Wisconsin (https://www.mypcnow.org/pedfastfacts) provides fast facts on pediatric issues.

must be taken into account. Parental participation is essential in assessments and treatment. Nurses must have a dynamic process of assessment, treatment, evaluation, documentation, and communication with the child, parents, and interdisciplinary team members. Children with palliative care needs often have multiple providers in healthcare settings, schools, and social services. A care coordinator, either a nurse or a social worker, can improve communications between settings.

Underlying Causes of Symptoms and Goals of Care

With any new or ongoing symptoms, nurses need to be keenly aware of the pathophysiologic causes that may be causing or contributing to the symptom. In addition, the burdens and benefits of any investigation and/or potential treatment resulting from the investigation must be weighed. It is vital that healthcare providers do their best to ensure the family understands the stage of the child's illness. Although prognostication is fraught with many inaccuracies, especially in pediatric illness, children and families deserve some context.

Tensions may arise between different members of the healthcare team and even between family members in terms of how aggressively to pursue treatments or interventions. Some may see the benefits outweighing the burdens, while others may feel the benefits are too burdensome. Palliative care teams are experts in helping to navigate these types of situations.

Informed recommendations provided by pediatric palliative care clinicians can help families make the best decisions for the child in terms of location of care, intensity of treatment, goals of care, and support regarding advance care planning. For example, twice weekly blood transfusions for a child with a good QOL would likely be worth the burden, whereas for an unresponsive child at the end of life, it likely would not. However, each situation is unique, and the team and family together should make the best choice for the child.

Treatment of Symptoms

Symptom management must include both nonpharmacological interventions and pharmacological interventions.[15] A step-wise approach to increase interventions in response to the nature and severity of the symptoms is often used. This reduces the potential of overwhelming the family with too many choices all at once. Once symptoms are brought under control, the interventions can be tapered to determine which ones are most effective. An example of a symptom management algorithm can be seen in Figure 58.1.

Nonpharmacological or Integrative Therapies

> "Look, I am already taking nine medications and I am just a kid! Even adults won't want to take that many medicines."
>
> —10-year-old cancer patient

Nonpharmacological and integrative modalities are commonly used by parents and children with reported good effect for relief of adverse symptoms.[16] This can include cultural or religious interventions and can enhance or even provide better relief than the medication. It is important for the healthcare team to be aware of nonpharmacological interventions which may adversely interact with medications and treatment protocols. Exchanging information in an unbiased manner allows for clinicians and parents to hear about the potential benefits and burdens of any given treatment.

Mind–body modalities rely on the body's ability to self-regulate. Common practices include prayer, hypnosis, biofeedback, mental imagery, and music therapy. Hypnosis is best understood as an alternative state of awareness,[17] one of concentration and intense focus. Children have active imaginations that help them enter into a world of "make believe."[18]

Clinical hypnosis has proved useful for pain and symptom management, including nausea, in pediatric palliative care as well as for painful procedures such as lumbar punctures and blood draws.[18]

Music can bring comfort and distraction. Many parents sing songs or recite rhymes for young children, while older children may listen to music on headphones. Music therapists offer insight into deepening the effectiveness of this intervention.[19] Nurses can encourage parents to use this modality.

Biologically based integrative modalities include herbs, supplements, and related nutritional therapies. "Natural" does not guarantee safety; supplements can interact with other medications, have adverse effects, or even cause toxicity. A trusting relationship between the nurse and parents allows honest sharing to discuss the burdens, cost, and potentially unrealistic hope for cure.

Aromatherapy generally involves diluted topical application or inhalation of an essential oil. It is thought that topical essential oils can reduce pain and inflammation and that inhaled oils act on the central nervous system to produce a calming or arousing effect via the limbic system. Essential oils can also be a way to invoke

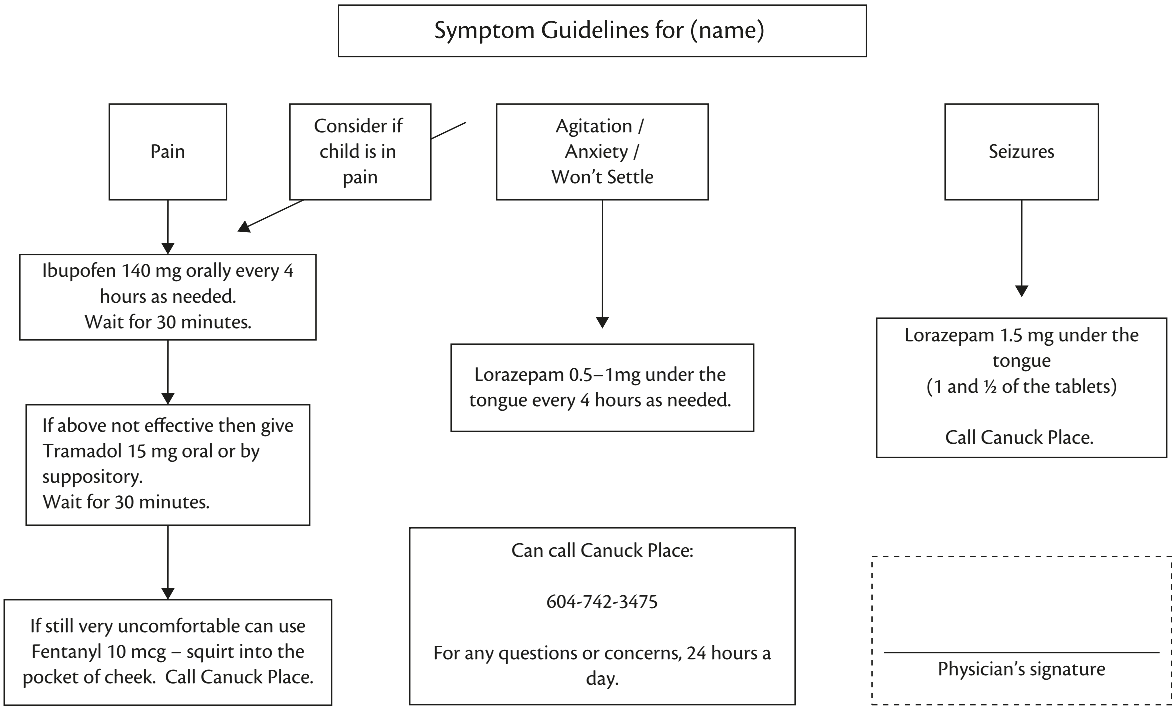
Symptom Guidelines for (name)
Pain
Consider if child is in pain
Agitation / Anxiety / Won't Settle
Seizures
Ibupofen 140 mg orally every 4 hours as needed. Wait for 30 minutes.
If above not effective then give Tramadol 15 mg oral or by suppository. Wait for 30 minutes.
If still very uncomfortable can use Fentanyl 10 mcg – squirt into the pocket of cheek. Call Canuck Place.
Lorazepam 0.5–1mg under the tongue every 4 hours as needed.
Can call Canuck Place:
604-742-3475
For any questions or concerns, 24 hours a day.
Lorazepam 1.5 mg under the tongue (1 and ½ of the tablets)
Call Canuck Place.
Physician's signature

Figure 58.1 Symptom guidelines. Example of a symptom algorithm from Canuck Place, Canada.

memories or to distract from noxious smells. Inhaled aromatherapy can be delivered via an infuser or simply by taping a cotton ball saturated with the oil to a pillow case. Lavender is typically used for relaxation.[20] Oral peppermint may relieve gas, and oral ginger may alleviate nausea.[21] Although aromatherapy is not well researched,[20] it is easy to use and has few adverse effects.

Manipulation and body-based therapies include techniques like massage, chiropractic, acupuncture, acupressure, and other forms of physical manipulation that may be used in consultation with the treating team. Practitioners experienced with children are preferred. Some express concerns that acupuncture needles many add to the child's distress, but there is some research that has shown that it is well-tolerated and effective.[22]

Energy therapies include esoteric arts, such as Reiki, healing touch, craniosacral therapy, Chi Gong, and related arts. These interventions involve a trained practitioner employing techniques to manipulate the naturally occurring energy fields or life energy within and around the body. These techniques are noninvasive, rarely cause complications, and can produce a sense of calm or relaxation. However, some families are not comfortable with these therapies.

Pharmacotherapy

Generally, the medications utilized for symptom management in pediatric palliative care are the same as those for adult palliative care, albeit with specific dosing recommendations. For example, neonates have limited ability to metabolize or excrete certain medications, often requiring low doses of medications which change as they mature. Medication doses are not included in this chapter but may be found online or in databases (e.g., Lexicomp or Epocrates). It is helpful for nurses to have ready access to the local children's hospital formulary and cross-reference with other resources (e.g., hospital or community pharmacist), as new information and safety considerations are informing practice all the time.

Nurses also need to consider which route of administration is most appropriate for the child, taking into account the compatibilities of medications, adverse effects, and the benefit/burden at any given interval in the child's trajectory. Medications should be selected in the context of the child and family. Rectal administration may be unacceptable for some families. Sensitive education may help a family agree to try a method or medication that is initially unacceptable; however, family members should never be pressured or made to feel guilty for their decisions.

Dyspnea/Respiratory Distress

Dyspnea is the subjective feeling of being short of breath. Respiratory distress can be observed by others as a symptom that includes increased work of breathing, decreased ability to exert oneself, panic, or agitation. In babies, retraction of the ribs and head bobbing is often observed. Parents often describe dyspnea as one of the most difficult symptoms to witness in their child, and many voice concerns about their child feeling like he or she is suffocating. Dyspnea must be anticipated and responded to quickly. Dyspneic symptoms can present at any age and with a variety of conditions; anticipation of dyspnea is essential in care planning. It is the nurse's role to ensure that the parents can assess respiratory distress, treat with nonpharmacologic interventions (fan, cool room, positioning), and escalate the medications safely and confidently. Opioids and benzodiazepines are first-line options for managing dyspnea.[23] Different agents have different pharmacokinetic profiles and are therefore suitable for certain situations. For temporary breathlessness that occurs with increases in activity (such as during a shower), a quick-acting, ultra-short-acting opioid such as sublingual fentanyl is an appropriate choice. Writing an algorithm for staff and family provides a guide to which interventions can be escalated; a breakthrough dose may be needed if background medications are insufficient.

Case Study: A Pediatric Patient with Dyspnea and Panic

Rachel is a 17-year-old with metastatic osteosarcoma and extensive lung disease. Recently, she has experienced increasing work of breathing with activity. She was having difficulty getting to class using her crutches, and showers were exhausting. She was more comfortable when sitting and found a handheld fan helpful for dyspnea. She had a mild cough but no secretions, fever, or nasal congestion. Her hope was to continue to attend school. Rachel started on 5 mg of immediate-release morphine to be taken hourly as needed. A salbutamol inhaler every 4 hours as needed decreased her cough. After a few days, her morphine was converted to a long-acting formulation of 30 mg every 12 hours (she had used an average of 12 breakthrough doses/day) with a breakthrough dose of 3 mg every hour as needed. This provided much better control of her dyspnea.

Rachel's dyspnea continued to worsen over several weeks, especially at night when prone. She was struggling to arise, shower, and get to class. The breakthrough doses helped but left her drowsy and unable to pay attention in class. Rachel was getting weaker. She found that the short-acting opioid fentanyl 25 mcg sublingually prior to exertion reduced her dyspnea without making her "zoned-out." A fan at her bedside was helpful, while oxygen was not. She agreed to try lorazepam 1 mg as needed and relaxation tapes.

As the dyspnea got more severe, her panic increased. She identified that it was not only the sensation of feeling breathless but was also due to her sadness and fear of knowing she was dying. She said talking helped sometimes. Other times, she just wanted her mom to hold her hand and look at old photos. The lorazepam helped control the overwhelming fear. Meditating to a safer place, which she identified as a beach setting with a cool breeze, was also helpful for her. By having a number of interventions to use, Rachel was able to control her dyspnea and improve her comfort.

Excessive Secretions Can Cause Respiratory Distress

Secretions can be problematic at different times across the child's palliative journey and do not need to be treated unless causing distress. Increased salivation is very common in children with neuromuscular disorders such as cerebral palsy. At times, a dry bib will suffice, but drooling/excessive secretions can cause perioral dermatitis, dental problems, dehydration, respiratory distress, and aspiration pneumonia.[24] Thick secretions may be hard to mobilize and cause respiratory issues, but increased humidity or nebulized saline can be helpful.

As with other symptoms, it is vital to assess whether any of the treatments or medications are exacerbating the problem. Excessive medical hydration can cause increased oral secretions,[25] and this issue needs to be examined carefully. Nonpharmacological measures to treat excessive secretions include adjusting fluid intake, positioning, and good pulmonary toilet.

If chronic and problematic, secretions can be managed with oral anticholinergic agents such as glycopyrrolate[26] or hyoscine, and atropine 1% ophthalmic drops can be used orally. However, adverse effects, such as thick secretions and urinary retention, can occur. In some children, injection of Botulinum toxin (Botox) into the salivary gland can be helpful to reduce secretions.[24]

At the end of life, some children have secretions that collect in the back of the throat as the swallowing muscles become too weak to function. The associated gurgling noise can be very distressing for family members. The nurse can help family members recognize signs of distress in the child's face and know which comfort medications should be given to help relieve the symptoms as much as possible.

Case Study: A Patient with Excessive Secretions

At age 3 years, Ali was diagnosed with a neurodegenerative condition. He slowly lost his ability to swallow. A gastrostomy tube was inserted for nutrition. His increased secretions irritated his face, and neck requiring frequent clothing changes. Barrier creams and bibs helped for a short time but frequent aspiration pneumonia and chronic sores in the folds of his neck became serious complications. Oral glycopyrrolate was prescribed and, later in his disease course, sublingual atropine and Botox injections to his salivary glands were employed but did not resolve the issue. The family chose no other aggressive interventions. As Ali's disease progressed, the secretions increased, requiring suctioning every 10–15 minutes, while his gastrostomy feeds continued at the same rate. Palliative care staff talked with the family about the burdens of overhydration causing increased secretions at end of life. Ali's mother said she would allow Ali to "tell her" when he had too much by the amount of secretion he was experiencing. With the technique of "feed to comfort," his comfort level improved.

Gastrointestinal Symptoms

Nausea/Vomiting

Nausea is a complex symptom with a wide variety of causes.[27] It can be caused by chemicals such as drugs or toxins, central nervous system abnormalities, vestibular changes, and multiple issues in the gastrointestinal tract including constipation. When the underlying cause can be identified, it will determine the most effective intervention. A careful assessment is essential.

Psychosocial and emotional aspects play a significant role in gastrointestinal symptoms and managing anxiety, anger, and other stressful emotions can provide relief of these symptoms. Therefore, a very careful history and assessment, involving the parent and, if possible, the child, is essential. Understanding the frequency, duration, and timing of nausea/retching or vomiting can help delineate contributing factors, but further investigation may be needed.

Reducing intestinal distention can relieve nausea, retching, or vomiting. Regular bowel movements are key. For some children, this may mean multiple bowel movements in a day. Children who receive their nutrition orally have control over their intake, while those who are "tube-fed" do not. It is important to adjust the amount and rate of the feeding to the child. Children with severe neurological impairment often have lower energy requirements than healthy children, and overfeeding may cause abdominal distention and discomfort.[28] In collaboration with their managing team, families may try Pedialyte, adjusting the rate and concentration of formula, or try temporarily stopping the medically provided nutrition.

Hypnosis, music therapy, and aromatherapy can be tried. Acupressure is commonly used for nausea. The pressure point for nausea control is the P6 or Neiguan pressure point. This is on the inside of the forearm three of the child's finger widths distance from the wrist crease.[29] Elastic straps (Sea-Bands) that provide continuous gentle pressure are available, and intermittent pressure on the P6, or for older children, a dried bean—a "magic bean"—taped on to the P6 point works well. Research has shown that acupuncture is well tolerated and effective for nausea as well.[30]

Peppermint, chamomile, fennel, ginger, or other mild teas may settle an upset stomach. Chicken soup, tea and toast, or family remedies, although not scientifically proven, may be helpful. The power of the placebo is not to be ignored.

Establishing the cause of the nausea, if possible, will determine the medications used. Some common medications used for nausea and vomiting include dimenhydrinate, 5HT-3-receptor antagonists (e.g., ondansetron), corticosteroids (e.g., dexamethasone), benzodiazepines (e.g., lorazepam), and prokinetics (e.g., domperidone). Note that these medications can cause extrapyramidal effects. The best route for medications is the one that is simplest and most acceptable for the child and family. This may be intravenous, rectal, sublingual, or transdermal.

Case Study: A Patient with Nausea

Olivia was a 6-year-old with a rare fatal condition. Olivia's mother reported that her daughter was complaining of feeling sick. After a thorough assessment, no clear physical reasons were evident. Oliva said when her mother left the room, "My fish died and we flushed him down the toilet. That is what happens when you die! I heard the Doctor tell mama that I might die. If I die, will they flush me down the toilet?"

The team, including a child life professional and a massage and music therapist worked with Olivia's mother to give her age-appropriate information to address the anxiety. Further medical tests were discussed with the family to ensure all aspects of this symptom were addressed.

Constipation: Prevention Is Better Than Cure

"My nurse is always asking about poop!!" said an 8-year-old boy in hospice. Each child's normal bowel routine is different and constipation must be assessed in that context. Assessment of the cause, history, and usual bowel habits will guide the interventions suggested to the family. Constipation commonly occurs secondary to medications, neurological disorder, and disease process. In mild cases, pear juice, prune juice, increased fiber and fluids, or a bulk-forming laxative can be effective. When constipation is more severe or long-standing, polyethylene glycol powder, stimulant laxatives such as senna or bisacodyl, and lactulose can be used. The dosage and formulation will depend on the child's weight and ability to swallow. In younger children, rectal medications may be the simplest solution to treat constipation, whereas older children typically dislike rectal administration. Sodium phosphate enemas and glycerin or stimulant suppositories can be used if there is impaction but not obstruction. When tumor obstruction or structural abnormalities are present, surgery or subcutaneous injections of octreotide may be used. In cases of severe opioid-induced constipation, intravenous methylnaltrexone can be effective.[31] A sample of a constipation algorithm can be found in the CPCH Symptom Assessment Guidelines.

Case Study: A Patient with Constipation

Jennifer was a single mother of Tyler, who had encephalopathy secondary to birth asphyxia. He was fed by gastrostomy tube. During one home visit with the nurse, Jennifer mentioned that Tyler has started vomiting after his feeds. On further discussion, she reported he had not had a bowel movement for 1 week. The nurse discussed the possible connection between the vomiting and constipation. Polyethylene glycol was prescribed, but Jennifer preferred to give him prune juice, which worked well.

Feeding Difficulties/Appetite Issues

Across all ages and many cultures, food is symbolic of love and interconnectedness. Intake of food is seen as the most basic human need. When disease or treatments decrease the child's appetite, families are distressed, even if the child is not. A careful assessment of medications, nutritional history, physical condition, and disease process must be done. This may reveal rectifiable issues such as poor oral hygiene, mouth sores, or dental issues that can contribute to nutritional problems. Finances may prevent families from access to nutritious food, but they may hesitate to mention this. Social workers can be particularly helpful in these situations. Appetite stimulants have a role in some cases but may have adverse effects.

A child's inability to eat can be mistakenly interpreted as a personal rejection or giving up. For some families, food becomes a point of great discord, and parents may pressure the child to eat, resulting in frustration for both. The nurse must gently listen, educate, and support the family at this difficult time, helping them to find ways to reduce stress around eating. Small frequent snacks may be more palatable for the child. Families can be encouraged to find other ways to share their love for each other when food is not involved, such as watching a special movie together, doing an activity, or sharing story time.

In children whose condition is close to the end of life, weight loss is part of the natural process of the body shutting down; therefore, monitoring weight is less important and can cause family distress. However, an accurate weight may be needed to prescribe new medications.

Children who receive long-term medical nutrition and hydration (MHN) via medical interventions (e.g., gastrostomy, jejunostomy, or parenteral infusions) do not have the natural control over their body's intake. At the end of life, MHN can be more burdensome than beneficial. This may be shown in increased edema, vomiting, and increased secretions.[32] At this point, the team needs to help the family reidentify their goals of care and determine what actions would be most effective. The family can learn to adapt the interventions to meet those goals. Often, this is a long process, as families and the team adjust the rate, frequency, amount, and type of formula in an attempt to find what other forms of nutrition the child can benefit from before accepting the child's change in condition. At times a "feed to comfort" medical order may be needed to relieve the child of the suffering from an inability to process MNH.

Figure 58.2 Morning glory.

Box 58.2 Neuro-irritability Assessment

A child may have neuro-irritability if:

- Actions known not to be painful (wearing socks, touching) seem to cause pain or distress
- Child fusses or cries for no apparent reason
- Child's crying is difficult to control or is prolonged
- Parent cannot tell the difference between the child's cries for attention and cries due to pain/discomfort
- Child's pain/discomfort cannot be localized

Nonpharmacological Measures for Inconsolability

- Environment: Quiet, dim lighting; rested parents
- Swaddling
- Music therapy
- Aromatherapy: Lavender oil diffuser or drop on a cotton ball on the pillow
- Massage
- Prayer
- Rocking: Infant swing, rocking chair
- Therapeutic touch or Reiki

Source: Adapted with permission from Reference 34.

This type of order allows for feeding flexibility to adjust to the child's comfort, even if that means decreasing or stopping feeds. This period is a sensitive and particularly difficult time as feeding is seen as an inherent part of providing care. The team's understanding, patience, and ongoing support for the family are essential at this time; it may be an issue that takes time to resolve. A spiritual care provider working in collaboration with the team can be of great support, particularly at the end of life when a child refuses to eat or cannot tolerate MNH.

At end of life, when a child's body is no longer able to tolerate nutrition or hydration, natural changes occur in the body. Children may start to look very gaunt or skinny, and the skin may be dry and loose, which can be upsetting. For some families, the analogy of the morning glory flower is helpful (Figure 58.2). This flower in full bloom is open but at the end of the day it closes and looks wrinkled and shrunken, yet it is the same flower inside.

The dying process can be very protracted. Dying infants have lived comfortably and very alertly for as long as 3 weeks without any medically administered nutrition or hydration. This can be an intense time of waiting and watching for the family and healthcare providers. The ongoing support of the team for both parties is essential.

Neurological Symptoms

Children with serious neurological impairment, with or without an underlying progressive condition, typically experience a complicated disease course, with times of stability interrupted by acute health decline and recovery, followed by a new plateau with an uncertain trajectory.[2] Seizures, increased tone or spasticity, and irritability wreak havoc on the QOL of the child and the family. The wide range of specialist teams involved can make sharing information a challenge. But, ideally, the various team members will coordinate and collaborate to create a care plan with parents.

A comfort log is an individualized tool for determining the extent or severity of the symptoms and the helpfulness of an intervention. They are easy to design and can be used during a hospital stay or at home. They can include descriptions of the symptom, duration, helpful interventions (pharmacological or nonpharmacological), and effect of interventions. This enables clinicians and family members to get an overview and assess the effectiveness of interventions. For example, the questions listed in the neuro-irritability assessment at the end of the chapter in Box 58.2 can be helpful for healthcare providers and family members to examine neuro-irritability symptoms. In assessing a child for neuro-irritability, it is also important to identify any signs of allodynia and hyperalgesia.[33] Benzodiazepines, gabapentin, or pregabalin, neuroleptics, and adrenergic agonists and antagonists are the medications most often used for neuro-irritability symptoms.[34]

Children who have increasing frequency of seizures or a potential to have a seizure (e.g., brain tumor) require a step-wise approach to management involving regular antiseizure medications (e.g., levetiracetam) and rescue medications (e.g., diazepam). An individualized algorithm that incorporates interventions and next steps is helpful. When there is potential for life-threatening seizures, clinicians have an obligation to discuss this with the family, so direction of care can be considered. For example, a child with a progressive brain tumor may need treatment for a seizure within the context of her dying. Part of the algorithm may explicitly state that the parent's role is to not only medicate the seizure, but also to hold and comfort the dying child. For children who are otherwise stable, the plan may include responding to the symptom with medication and then engaging emergency services for further treatment.

Emotional and Existential Distress

It is beyond the scope of this chapter to critically explore anxiety and depression from emotional and existential distress in children with palliative conditions. Children of any age may experience suffering during the dying process that goes beyond the physical.

Moreover, parents and children are connected in ways that are not like other relationships, with each influenced by the other in the face of ultimate physical separation.

Children of any age should be assessed from a developmental framework in regard to their emotional and spiritual health. Are they experiencing joy and times of pleasure and having opportunities to play and express themselves? What is it like to spend months in neonatal intensive care or receive chemotherapy? How are they adjusting to the changes in friendships and activities? What gives them hope and purpose?

Families and children have different capacities in which to communicate, find meaning, and adjust to the multitude of changes that serious illness brings. An interdisciplinary palliative care team can be instrumental in supporting the family unit and the child in these tasks. If physical symptoms can be controlled, it may allow the child and the family to better process the symptoms of emotional and spiritual distress. Often, families need coaching in how to listen to their children's questions about the changes in their body and how to respond with both honesty and hope. Children and parents may need different and separate confidants to share their questions, worries, and fears as a way to protect the other loved one.

When suffering in this realm is not responding to multiple attempts from family, community, healthcare providers, counseling professionals, spiritual support, and other therapy, medications such as long-acting antidepressants, benzodiazepines, antipsychotics, or stimulant medication may be helpful in the short or medium term.

Case Study: A Patient with Multiple Symptoms

Mya was born with a fatal genetic disorder and irreparable cardiac condition; she was expected to live only weeks to months after birth. The parents wanted comfort care only and were eager to go home.

They were happy to have her home, but struggled to cope with her long periods of crying. No curable causes for the crying could be found. The team was concerned that this was neuro-irritability, also known as *central neuropathy*. Nonpharmacological interventions along with an over-the-counter medication were tried. These helped but did not resolve the problem.

There was parental resistance to medications, but, with further discussion they decided to "listen" to what Mya was "saying" she needed. Gabapentin was helpful during the day, and lorazepam at night allowed everyone to sleep.

While initially the parents did not want any tubes, they now feared she was hungry and requested a nasogastric tube be placed for extra feeds. The palliative care team taught the parents how to place the tube and had the family use a reliable YouTube video as an additional guide.

The extra feeds increased Mya's oral secretions, requiring frequent suctioning, and she began to vomit with feeds. None of the medications or adjustments prevented this. This was a difficult time for the family, but they decided to remove the tube and feed her orally. Mya was more comfortable and died peacefully.

Conclusion

> Blessed are the flexible for they shall not be bent out of shape.
> —An old Southern saying.

Although many of the symptoms commonly seen in dying children are similar to those in adult palliative patients, children are often less able to describe and localize their symptoms. Nurses must therefore be careful listeners, imaginative problem-solvers, and evidenced-based professionals. They need to be able to draw on a broad skill set, including excellent assessment, critical thinking, and communication skills, and flexibility.

The family must be closely integrated with the palliative care team as care planning and decision-making are done. If this collaboration is not present, success may be difficult. Building trusting relationships is vital to ensure excellent care with the designated "family" of the child, the medical team, and community resources.

Nonpharmacologic interventions, medication dosages, and routes of administration must be tailored to the child and family. Acceptance of the care can be influenced by culture, religion, past experiences, and the child's stage of development. Evidence-based clinical guidelines and algorithms can be helpful as a starting point for the individualized care plans.

Pediatric symptom management can be complex and challenging but often rewarding, as you see a child and family move from a focus on the distressing symptom to an improved QOL.

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CHAPTER 59

Pediatric Hospice and Palliative Care

Vanessa Battista and Gwenn LaRagione

Key Points

- Pediatric palliative and hospice care (PPHC) is multifaceted care that focuses on a child's and family's well-being along a physical, psychological, emotional, spiritual, and social continuum.
- Pediatric hospice should be considered a necessary part of comprehensive palliative care.
- Pediatric palliative care (PPC) involves a family-centered approach to caring for infants, children, and adolescents and considers all family members as part of a dynamic web of interconnected lives and relationships.
- Initial and ongoing education and care delivered by an interdisciplinary team (IDT) of healthcare professionals is essential in addressing the complex physical, emotional, spiritual, and practical needs and concerns of children and their families.
- Relieving suffering and improving quality of life, for even a brief life, can benefit not only the child, but all those affected by the illness or death of the child, including siblings, parents, grandparents, other relatives, teachers, school friends, faith community, and neighbors, as well as the healthcare professionals involved in their care.
- Nurses who care for dying children and their families need a significant personal and professional support system and opportunities for renewal, personal growth, and ongoing education.
- PPHC is a rapidly developing field with many opportunities for growth and expansion.

Overview of Pediatric Hospice and Palliative Care

Universally, children symbolize the "future," representing dreams and the promise of accomplishments yet to be fulfilled. The experience of serious illness or the death of an infant, child, or adolescent (referred to collectively as "children" for the purposes of this chapter) therefore generates a legitimate threat to such hopes. Bearing witness to these experiences motivates clinicians to do their best to prevent and relieve the suffering of children likely to die, both through interventions aimed at cure and, when cure is no longer possible, through the provision of interdisciplinary pediatric hospice and palliative care (PPHC). PPHC is an area of nursing that requires specialized knowledge and training and great sensitivity to the unique needs of families enduring some of the most arduous moments of their lives. Providing this type of care throughout the illness process, from the time of diagnosis until the time of death, can be simultaneously physically and emotionally challenging, as well as enriching and rewarding. This chapter provides an overview of PPHC and the special considerations necessary for nurses who are called on to provide this unique type of care for children and their families.

Definition of Pediatric Palliative Care

The World Health Organization (WHO) developed one of the earliest and most widely accepted definitions of pediatric palliative care (PPC), describing it as the active total care of the child's body, mind, and spirit and involving an evaluation of a child's psychological, physical, and social distress.[1] That definition has since evolved to include care aimed at improving quality of life (QOL) of patients facing life-threatening illnesses and of their families through the prevention and relief of suffering by early identification and treatment of pain and other problems, whether physical, psychological, social, or spiritual.[1] The American Academy of Pediatrics defines PPC as care that should aim to achieve the best QOL for patients and families consistent with their values.[2] The Institute of Medicine states that PPC should consider the needs of patients and families in order to provide timely, accurate, and compassionate information regarding diagnosis, prognosis, and treatment options.[3] As the field of PPC has advanced over the past decade, understanding the emotional well-being of the child and family and the importance of an interdisciplinary approach to care have been incorporated in defining optimal PPC.[4,5]

Combining all of these definitions, PPC can be described generally as a family-centered approach to care that encompasses the physical, psychological, emotional, social, and spiritual components of a child's needs and focuses on overall QOL. Ideally, PPC should be provided by an interdisciplinary team (IDT) of professionals from medicine, nursing, psychiatry, psychology, social work, chaplaincy, child life, physical/occupational/speech therapy, art and music therapy, nutrition, pharmacy, and other areas of healthcare (e.g., integrative health and other therapies). PPC offers expert pain and symptom prevention and management and honest discussion around the child's medical condition, which serves as the foundation for collaborative decision-making regarding goals of care. This child-focused, family-centered, holistic care should be initiated as early as possible in the illness trajectory in order to provide the child and family with the opportunity to receive support that will enhance their capacity to cope with a life-threatening or life-limiting condition. PPC aims to preserve the integrity of the family throughout disease progression, addresses anticipatory grief, and also includes bereavement support following death.

Definition and Evolution of Hospice Care

The word "hospice" is thought to have originated in the early eleventh century, stemming from the Latin word *hospes* or *hosptium*, meaning "guest house" and referring to both guests and hosts.[6] The National Hospice and Palliative Care Organization (NHPCO) describes hospice as a model of care designed to provide quality compassionate care to people with a life-threatening/-limiting illness that centers around their individual needs and wishes and is delivered through a team approach (e.g., pain and symptom management and medical, spiritual, and psychosocial care/support). Hospice care focuses on caring for, not curing, the patient while also providing support to family, friends, loved ones, and communities.[7]

The modern hospice movement began with Dame Cicely Saunders, trained as a registered nurse, social worker, and physician, who founded St. Christopher's Hospice in the United Kingdom in 1967. As her career evolved, so did her realization that a dying person needs more than symptom management; she felt they needed a holistic approach to care; that is, they needed to be treated medically, physically, emotionally, spiritually, and socially. She also pioneered the development of bereavement services, as she recognized that the patient and family were a single entity that needed support both during the dying process and after the death of the patient.[8]

As the hospice philosophy and movement grew throughout the United Kingdom and into the United States, Medicare recognized the need to cover hospice services and introduced the hospice benefit in 1983. The benefit was designed to provide nursing care, medications, medical supplies, psychosocial support, and volunteer services for end-of-life (EOL) care through a daily per diem reimbursement rate. To be eligible for the benefit, a patient had to have a life expectancy of 6 months or less, as defined by a physician, and had to relinquish aggressive, disease-related curative treatment in exchange for supportive care during the dying phase of life.[9] As a result, society's view of death and dying changed, an economic value was placed on dying, and EOL care became a public policy issue.

Comparing Pediatric Palliative and Hospice Care

The terms "palliative care" and "hospice care" are often used interchangeably (as in this chapter) because of their similar core values and philosophical approaches to care. However, it is important to appreciate and understand their distinctive features. Primarily, palliative care can be provided at any time during the course of the disease (including the time of diagnosis), whereas hospice care focuses more around true EOL care.[10]

When compared with adult care, there are many differences in the provision of PPHC, and the NHPCO's *Standards of Practice for Hospice Programs*, Appendix IV: Pediatric Palliative Care (see Box 59.1), provides in-depth insight into these differences. Most

Box 59.1 Patient- and Family-Centered Care (PPC PFC) Principle

The palliative care and/or hospice interdisciplinary team provides family-centered care that includes the child and family as one unit of care, respecting individual preferences, values, and cultural beliefs, with the child and family active in decision-making regarding goals and plan of care.

Patient and Family-Centered Care (PPC PFC) Standards

PPC PFC 1 The goals of the child and family are foremost at the center of all services provided.

PPC PFC 1.1 Services should be available to all children and families who are referred, regardless of their financial or health insurance status.

PPC PFC 1.2 Family is defined as the persons who provide physical, psychological, and spiritual comfort to the child, and who are close in knowledge, care, and affection—regardless of genetic relationships. Family members may be biological, marital, adoptive, custodial relations, friends, as well as pets. Parents, siblings, grandparents, schoolmates and others are part of the child's community who may need particular support.

PPC PFC 1.3 All aspects of care are provided in a manner that is sensitive to: the child's developmental stage; the personal, cultural, and spiritual beliefs and practices of the child and family; and their preparedness to deal with dying or its possibility.

PPC PFC 1.4 The child has the right to age-appropriate information about his or her illness, as well as potential treatments and outcomes, within the context of family decisions. The program has trained staff and a full range of clinical and educational resources that meet the needs of each child served regardless of age, cognitive and educational ability.

PPC PFC 1.5 The family and caregivers have the right to be informed about the illness, potential treatments and outcomes.

PPC PFC 1.6 Decisions are made by the family, including the child to the level of his/her capacity, in collaboration with the interdisciplinary team and additional service providers.

PPC PFC 2 Comprehensive anticipatory loss, grief and bereavement support methodologies are offered as an integral component of care to the child and all family members from diagnosis or at admission into the program.

PPC PFC 2.1 Methods to address loss, anticipatory grief and bereavement are age-appropriate and include information about the needs of dying and grieving children at all developmental stages.

PPC PFC 2.2 Educational materials describing children's grief and supportive strategies for bereaved children are made available to family members.

PPC PFC 2.3 Partnerships among palliative care providers and community agencies (e.g., schools, faith communities) are established to facilitate outreach and support for children affected by loss.

PPC PFC 2.4 The needs of siblings are an integral part of each child/family plan of care.

(*continued*)

Box 59.1 Continued

Ethical Behavior and Consumer Rights (PPC EBR) Principle

The best interests of the child shall be the primary consideration in decision-making.

Ethical Behavior and Consumer Rights (PPC EBR) Standards

PPC EBR 1 Staff communication with the child and family is open and honest, in accordance with each child's level of understanding. Without full disclosure, the child and family cannot participate in decision-making about treatment choices. When, what, and how to disclose information to children must take into account the child's and the family's cultural or religious values, the parents'/guardians' choices of what the child can be told, and the child's capacity and desire to understand.

PPC EBR 1.1 Every child has equal access to palliative care and/or hospice, irrespective of the family's financial circumstances.

PPC EBR 1.2 Children are not subjected to treatments that impose undue burden without potential benefit.

PPC EBR 1.3 Every child receives effective pain relief and symptom management, incorporating the use of pharmacological and non-pharmacological methods.

PPC EBR 1.4 Every child is treated with dignity and respect, and is afforded privacy.

PPC EBR 1.5 The needs of adolescents and young people and their role in decision-making are addressed and planned for, well in advance.

PPC EBR 1.6 The practice of physician-assisted suicide or euthanasia is not supported or endorsed.

PPC EBR 1.7 The principles of negotiation and conflict resolution are used to address disagreements among or between healthcare providers, the child and the child's family about disclosing information to the child.

PPC EBR 1.8 When resolution is not achieved, the interdisciplinary team enlists the assistance of a cultural interpreter/advisor, chaplain and/or an ethics consultant.

PPC EBR 1.9 In the event of an ethics consult, the team meets afterwards, with the family and/or child present *(as preferred by the child and his/her family)* to discuss options, and to assist in implementing changes to the plan of care.

PPC EBR 2 The interdisciplinary team provides guidance to the child/family in choosing medically and ethically appropriate treatment options that are consistent with their values and beliefs. Team members should not attempt to influence families to make decisions that are not compatible with their values. Children with chronic illness often have a level of understanding greater than would be assumed based on their age.

PPC EBR 2.1 Every child is given the opportunity to participate in decisions affecting his or her care, according to age, understanding, capacity and parental support.

Emphasizing competence or capacity to assent or dissent, rather than the age of the child, allows children to participate in decisions regarding their care whenever possible and appropriate.

PPC EBR 2.2 While most children under the age of 18 have no legal decision-making rights, they should be included in decision-making according to their capacity. For children without complete decision-making capacity, parents or guardians make decisions based on the best interests of the child, assisted by the interdisciplinary team.

PPC EBR 2.3 For older children who demonstrate some healthcare decision-making capacity, parents/guardians and the interdisciplinary team should share age-appropriate information, seek assent, and take into consideration dissent, while ensuring the child's best interests remain at the core of decisions.

PPC EBR 2.4 For adolescents under the age of 18 who demonstrate healthcare decision-making capacity, every effort must be made to obtain parental approval to include these children in the decision-making process, thus allowing them to exercise independence.

PPC EBR 2.5 Emancipated minors with demonstrated capacity have the legal right to participate in all decisions regarding their medical care.

PPC EBR 2.6 There is an established process for anticipating, identifying, and resolving conflict, including consultation with specialists and/or a bioethics committee.

Clinical Excellence and Safety (PPC CES) Principle

Health professionals providing pediatric palliative care and/or hospice have a responsibility to pursue comfort aggressively and minimize the child's physical, psychosocial, and spiritual pain and suffering.

Clinical Excellence and Safety (PPC CES) Standards

PPC CES 1 Clinical care will be guided by the ethical principles of beneficence, nonmaleficence and promotion of the best interests of the child.

PPC CES 1.1 In the absence of pediatric medical expertise, the palliative care and/or hospice organization will develop a collaborative consultative relationship with pediatric providers and/or a tertiary healthcare facility to support provision of care suited to the unique needs of pediatric patients.

PPC CES 1.2 A primary care coordinator for all pediatric patients is identified.

PPC CES 1.3 A plan for anticipated pain and symptom management is part of every plan of care.

PPC CES 1.4 Pain prevention and treatment should be anticipated for all procedures or interventions related to the plan of care. Procedures or interventions not related to the goals of care should be avoided.

(*continued*)

Box 59.1 Continued

PPC CES 1.5 Members of all disciplines providing direct services to children will complete annual competencies in pediatric pain and symptom management.

PPC CES 1.6 Utilization of age-appropriate assessment tools is confirmed in all documentation.

PPC CES 1.7 Pain and all distressing symptoms will be assessed on every visit, by each discipline.

PPC CES 1.8 Families, and the child as age-appropriate, will be educated about pain and symptom assessment and management as it relates to their child's plan of care. Education materials are made available at time of admission and/or when pain and symptoms occur.

PPC CES 1.9 A pediatric physician and/or pharmacist are available for consultation to the interdisciplinary team as needed.

PPC CES 1.10 Adequate doses of analgesics are administered "around the clock" and not only on an "as-needed" basis. Additional doses are given to treat breakthrough pain, or predicted intermittent exacerbation.

PPC CES 1.11 When indicated, a sufficient dose and an appropriate pharmacological formulation (for example, sustained-release preparation or continuous infusion) is chosen to enable children and their families to sleep through the night, without waking in pain or waking to take their medications.

PPC CES 1.12 The appropriate opioid dose is the dose that effectively relieves pain and is not based solely on doses per body weight.

PPC CES 1.13 Age-appropriate, non-pharmacological therapies are an integral part of the pain and symptom management plan of care.

Inclusion and Access (PPC IA) Standards

No pediatric-specific additions to this standard are suggested.

Organizational Excellence (PPC OE) Principle

Flexibility in pediatric program design and service delivery facilitates access to services for children. A pediatric palliative care and/or hospice model that offers multiple support services over time and across settings ensures enhanced access for this underserved population.

Organizational Excellence (PPC OE) Standards

PPC OE 1 Pediatric programs may serve patients in the perinatal period, infancy, childhood, adolescence and young adulthood. The program must have policies and procedures in place to address all developmental, physical, social, psychological and spiritual needs of children served.

PPC OE 1.1 Care by providers trained in pediatric palliative care and/or hospice is available 24 hours a day, 7 days a week.

PPC OE 1.2 Families have a key contact person to assist with coordination of care, and they are instructed on how to contact the team in the event of a crisis or if they have needs after designated business hours.

PPC OE 1.3 Coordination of care among the interdisciplinary team, the family, and all sites of care occurs regularly and is discussed routinely at interdisciplinary team meetings.

PPC OE 1.4 Pediatric palliative care and/or hospice services are accessible to children and families in a setting that is appropriate to their needs and resources.

PPC OE 1.5 Respite care is recognized as a valuable need and the team makes every effort to ensure that families have access to respite care in their own home and/or in a home-away-from-home setting or facility with pediatric interdisciplinary care.

PPC OE 2 The program partners with community agencies and others that provide resources for children.

PPC OE 2.1 The program partners with local schools.

PPC OE 2.2 The program partners with social service agencies.

PPC OE 2.3 The program partners with specialty healthcare agencies.

PPC OE 2.4 The program partners with faith groups in the community.

Workforce Excellence (PPC WE) Principle

The organization's leadership develops and monitors systems to ensure that pediatric palliative care and/or hospice interdisciplinary team members, including volunteers, are adequately trained, staffed and supported to provide the services offered by the program, and that sufficient support is in place for staff to engage in routine self-care.

Workforce Excellence (PPC WE) Standards

PPC WE 1 All staff caring for children receive pediatric-specific orientation, training, mentoring, development opportunities and continuing education appropriate to their roles and responsibilities.

PPC WE 1.1 Pediatric-specific training is completed by all staff caring for children with life-threatening conditions.

PPC WE 1.2 Volunteers directly working with children or their families are also trained in developmental needs, family dynamics, communication challenges, and pain and symptom management.

PPC WE 1.3 When pediatric providers are not available within an organization, partnerships or consultative agreements are established with those in the community and/or at tertiary healthcare centers who are experts in working with children and adolescents.

PPC WE 1.4 Clinical policies and procedures are developed and implemented for the care of children of any age. Policies and procedures reflect evidence-based pediatric practice and guide the provision of care by all disciplines.

(*continued*)

Box 59.1 Continued

PPC WE 1.5 On-call or after-hours staff are competent to take pediatric calls and provide pediatric care.
PPC WE 1.6 Pediatric consultative support is made available to staff as needed 24 hours/day.
PPC WE 2 Pediatric visit frequency and length of visit is assessed and adjusted to reflect the needs of both the child and family in the plan of care.

Standards (PPC S) Principle

Palliative care and/or hospice programs adopt the NHPCO Standards of Practice for Hospice Programs, and utilize the appendix "Standards of Practice for Pediatric Palliative Care and Hospice" as the foundation for their pediatric care.

Compliance with Laws and Regulations (PPC CLR) Standards

No pediatric-specific additions to this standard are suggested.

Stewardship and Accountability (PPC SA) Standards

No pediatric-specific additions to this standard are suggested.

Performance Measurement (PPC PM) Principle

The program develops, defines and utilizes a systematic approach to improving performance. This approach is authorized and supported by the program's governing body and leaders. The approach assures that information is collected and analyzed, actively uses performance measurement data to foster quality assessment performance improvement, and is specific to pediatric patients being served.

Performance Measurement (PPC PM) Standards

PPC PM 1 The palliative care and/or hospice organization has a quality improvement plan in place to measure and evaluate services rendered to children and their families.
PPC PM 1.1 Measures of children's clinical outcomes are developed.
PPC PM 1.2 All adverse events are documented and investigated.
PPC PM 1.3 All medication errors are documented and investigated.
PPC PM 1.4 Resource utilization is analyzed.
PPC PM 1.5 Child and family satisfaction surveys are developed and sent to families.

Source: https://www.nhpco.org/sites/default/files/public/quality/Ped_Pall_Care%20_Standard.pdf.pdf

notably, PPC is unique because children go through developmental stages while having more complex, lifelong chronic conditions, thereby complicating the identification of treatment plans, trajectories, and ethical issues around legal decision-making, all while dealing with larger community involvement, less palliative and hospice care resources, and more complicated grief.[11]

Concurrent Care

When first developed, state and federal regulations and standards governing hospice care and the clinical guidelines for ongoing appropriateness (Medicare and Medicaid) did not address pediatrics. Determining the required 6-months-or-less prognosis is extremely difficult for pediatric physicians because of the wide variability of prognoses in children, often varying from days to weeks or from months to years. Referral to hospice care by physicians made them feel as though they were "giving up."

In addition, there was a question as to what, if any, treatments might be acceptable under hospice admission guidelines. Programs varied on whether blood products, antibiotics, infusions, lab tests, and more were considered "too aggressive" an approach to care, expecting parents to surrender all means of therapies before enrollment in hospice. These interventions were also a great financial burden or unfeasible for many programs without substantial foundational support, as most hospice programs did not have the financial allowance to provide these more liberal interpretations. The option of forgoing treatment in order for their child to receive palliative or hospice care was simply too difficult a decision for parents to make.

The US government has since responded with the enactment of the provision "Concurrent Care for Children" in Section 2302 of the Patient Protection and Affordable Healthcare Act (PPACA) on March 23, 2010.[12] This provision allows patients with state Medicaid or Children's Health Insurance Programs (CHIP) to receive hospice care while still receiving curative treatment. Its ratification demonstrated that healthcare systems and government better understand that the needs of children with life-threatening illnesses/conditions are distinctly different from those of adults.

To better understand and interpret this new act, in 2012, a pediatric-focused Continuum Briefing titled "Pediatric Concurrent Care" was composed at the Mary J. Labyak Institute for Innovation at the National Center for Care at the End-of-Life. This briefing included some barriers to the provision: (1) a physician still needs to certify that the child is expected to die in less than 6 months, (2) every state has different Medicaid covered services/resources, and (3) the provision itself does not specify what treatments/services are deemed curative.[13] The District of Columbia Pediatric Palliative

Care Collaborative and the National Hospice and Palliative Care Organization also recognized these barriers, as well as the effort involved for individual states to acclimate to and utilize concurrent care. In response, they developed a Concurrent Care for Children Implementation Toolkit, designed to guide providers and interested parties in understanding the effect that concurrent care could have on their individual state Medicaid programs. It describes how each state has its own amendment and waiver options and encourages learning from other states' experiences to help facilitate a statewide collaborative approach in adapting and implementing effective and efficient concurrent PPC services.[14]

In "Concurrent Care for the Medically Complex Child: Lessons of Implementation," Miller, LaRagione, Kang, and Feudtner[15] discussed some general issues they identified in coordinating concurrent care for medically complex children. They found that, when adding hospice services to care, existing providers (some who cared for the patient for many years) needed much education and support regarding the concept and the clinical interventions/treatment. They also discovered a high level of complexity in coordinating and integrating hospice care with the current services and providers already in place. Frequent and ongoing communication was necessary to ensure a safe and effective interdisciplinary approach to care. Last, determining who was responsible to provide equipment, either the current durable medical equipment company or hospice agency, and what services were still covered under the primary commercial insurance (if applicable) was challenging and complex. Despite these issues and challenges, Miller et al. found the effort worthwhile in helping to improve palliative and EOL care.[15]

Progress and Challenges

The advancement of palliative care as a model for care in the United States has reached unprecedented levels in many types of settings. Following that surge is now a robust effort to develop and integrate programs and services for those facing a life-threatening condition from a prenatal diagnosis of a lethal condition to young adults on the brink of adulthood. Growth has been evidenced on many fronts: legislative action, research, hospital-based palliative care, community-based hospice teams/programs, and specialty areas of palliative care, such as prenatal palliative care and palliative care in the emergency setting. Palliative and end-of-life care–specific curricula have now been integrated into many nursing and medical school programs, and several educational models and programs exist for clinicians to better understand the role of PPC and how to best provide this type of care. Despite this, many challenges to delivering optimal PPC and improving the QOL of children and families still exist. Much work remains regarding understanding the differences between palliative care and hospice, clearly defining the population being served, better understanding the needs of children with life-threatening conditions and of their families, developing an approach that will be appropriate across different communities, and providing timely care that responds adequately to suffering.[16] Changing the pervasive stigma of how PPC and hospice are often perceived by the general public and healthcare professionals as synonymous with "no more hope," "giving up," "there's nothing more that can be done," or "death must be near," is a long-term goal.

The ongoing painful dilemmas and struggles for families with children who are facing life-threatening illness and end of life remain hidden from society's view, yet the demands and challenges of caring for a dying child are being addressed continually within hospitals and homes. Individuals, institutions, universities, and community organizations, including hospices, are making a difference in addressing the needs of children with life-threatening illnesses in their communities. One of the most difficult parts of providing PPC, however, is that this type of care is often necessary at the beginning of young lives, a stage of life when almost anyone is naturally uncomfortable with the idea of serious illness or the concept of end of life. Nurses are instrumental in incorporating this contradiction of beginnings and endings into a realistic and compassionate framework for the care of children and families dealing with life-threatening or life-limiting illnesses. The landmark report from the Institute of Medicine, *When Children Die: Improving Palliative and End-of-Life Care of Children and Their Families*, set forward the challenge and a "call to action" to improve all aspects of EOL care for children and families, including improved quality and access to pediatric hospice.[3] It became the catalyst for a cascade of national initiatives, research, funding, and heightened awareness that continues to evolve today. In addition, the National Consensus Project Guidelines for Quality Palliative Care, originally published in 2004, provide clinical practice guidelines to foster consistent and high standards in palliative care and to encourage continuity of care across settings for both children and adults living with life-threatening illness.[17]

The ultimate goal, however, is not only to promote excellent PPC for children and families from the time of diagnosis through the time of death, but also to achieve success in heightening awareness of PPC in healthcare professionals and the general public. Improving QOL for even a brief life can benefit not only the child, but everyone affected by his or her death, which often extends beyond parents and siblings to grandparents, other relatives, teachers, friends, and community members, as well as to the many healthcare professionals who have been involved in the child's care and treatment. Each individual involved has played a unique role in the child's life, and the extensive constellation of those impacted by a child's illness and death may be exponentially greater than one might imagine. Often the individuals involved have not had any previous experience with the death of a child and thus an essential role for the PPC provider, and often the nurse directly caring for the child, is to provide guidance and support to other family members or professionals, especially when the goals of care change throughout the evolving journey of a child's illness, up to and including at the time of death.

The Settings where Pediatric Palliative Care Occurs

"Hospice and palliative care can be provided in almost any setting as long as those providing the care are willing to enter the patient's world and honor their setting of choice."[18(p. 310)] PPC can be implemented in a variety of inpatient and outpatient settings, including acute, chronic, intensive care units, emergency departments, long-term care facilities, at home, in school, and in communities. Irrespective of the setting, PPC should be patient-/family-centered, interdisciplinary, and collaborative with optimal and ongoing communication among all care givers.[19]

The American Academy of Pediatrics recommends that large healthcare organizations should have interdisciplinary PPC teams with expertise and experience to effectively manage and coordinate the complex and intricate arrangements in transitioning pediatric patients between healthcare and/or home settings while maintaining the highest quality of care possible.[20] Recommendations also include that these PPC teams stay involved and fully engaged across all settings to ensure continuity of care and appropriate treatment and interventions which align with the patient's and family's goals of care at all times.[20]

PPC nurses, advanced practice registered nurses (APRNs), and nurse coordinators have key roles within the interdisciplinary PPC team in transitioning patients across settings. They often have the most consistent, frequent, and intimate contact with the patient, family, healthcare providers, and community. They are key in the development of care plans and discharge plans that assure the patient is receiving the highest quality of palliative and EOL care in all settings.[19]

PPC for children living with chronic and/or serious illnesses should include aggressive and safe management of symptoms that help children and families feel well-supported at all times and across all settings.[18]

PPC and Hospice Service Availability

In evaluating the available outpatient PPC and hospice agencies that care for children, the NHPCO released facts and figures in their 2015 edition which found that, of the 4,000 hospice agency members surveyed, 78% reported that they served pediatric patients, with 36% having a pediatric program and 21.7% having staff members with pediatric experience.[21] The survey also revealed that the average number of pediatric patients who received palliative care were 0 to 10 and that those receiving hospice services were between 1 and 20.[21] Although there are fewer resources for pediatric patients than for adults, there is a growing interest in and number of resources to help care for children requiring PPC. The hope is to continue to build on this foundation both in quantity and quality of services.

Identifying the Children Who Could Benefit from Hospice and Palliative Care

The most recent data available report that a range of children can benefit from PPC, and it is estimated that more than 8,600 children have a need for PPC on any given day given their limited life expectancy and serious healthcare needs.[21] In the United States alone, there are about 50,000 pediatric deaths annually, and only about 5,000 children receive hospice services each year.[21]

There are four generally recognized pathways of conditions that lead to death in children. In brief, they are (1) life-threatening conditions for which curative treatment may be feasible but can fail (e.g., cancer, heart disease, trauma or sudden illness, or extreme prematurity); (2) conditions with inevitable premature death, often with long periods of intensive treatment aimed to prolong life and allow participation in normal childhood activities (e.g., cystic fibrosis, human immunodeficiency virus infection, chronic or severe respiratory failure, muscular dystrophy); (3) progressive conditions without curative treatment options, although children may live several years (e.g., severe metabolic disorders, certain chromosomal disorders, other rare diseases); and (4) irreversible but nonprogressive conditions with complex healthcare needs leading to complications and likely premature death (e.g., severe cerebral palsy, multiorgan dysfunction, severe pulmonary disability, multiple disabilities following brain or spinal cord infections, severe brain malformations). The illness trajectory of children can vary greatly depending on age and other factors, and, overall, the highest rate of death is reported as occurring in the first year, with a high proportion occurring in the first month of life.[3]

It is important to recognize that the type and length of a child's illness may impact the timing and ways in which PPC may be implemented and may also have an effect on how the family copes with the illness and/or death and the ways in which they grieve. For example, in the first group described, children may experience initial response to treatment, return of disease, and then poor to no response to treatments. Preoccupation with therapies, labs, or tests may overshadow any discussion about the possibility of dying, and focus remains on the tasks of managing the medical aspects of disease. Maximizing opportunities for comfort may be passed over or delayed in the intensive search for cure and life-extending alternatives. PPC may be necessary during periods of prognostic uncertainty, throughout the treatment course, and/or when treatment fails. In cases of death by trauma or accident, there may be little time to establish relationships, and immediate grief support might be the most helpful for the family. Conversely, children with very extended and variable pathways through illness, often referred to as *complex chronically ill children*, have multiple "peaks and valleys" and extensive needs over time. Life can become consumed by the constant focus on appointments, therapy, transportation, shift care, special needs, and ongoing obstacles to accessing adequate comprehensive care. Regardless of the particular condition or disease pathway, accessing PPC can be challenging for all the emotional reasons one might imagine when it is a child's life at stake. In some instances, the best introduction of PPC may be to emphasize the philosophy of comprehensive symptom management and simultaneous care for the body, mind, and spirit of both the child and family while shifting slowly from the sole focus of preserving life to measures to relieve suffering and maintain comfort. Nurses are often present for the highest ratio of time with the child and family and, along with others members of the IDT, have an extraordinary role in adeptly guiding families through this emotionally laden course.

Barriers to Accessing Pediatric Palliative and Hospice Care

Barriers to providing hospice or palliative care services for pediatric patients differ from those for adult patients. In general, society's belief that "children shouldn't die," along with denial of the process, make EOL care for this population a difficult and often misunderstood concept. Within the healthcare profession, a profound silence of discomfort and denial exists regarding babies and children dying. In many cases, healthcare professionals' attitudes and denial become the greatest barriers to their patients'/families' abilities to access additional options for expert palliative care and support services. In effect, this denies families the possibility of making an informed decision regarding the range of choices available during a child's illness. Clinical expertise in advanced illness or EOL care should be available for families who may transition their focus of care from a strictly curative mode to one of comfort and QOL.

In PPC, ethical issues, law, and policy are sensitive and complex and therefore create additional barriers that may intimidate providers regarding palliative and EOL care. Healthcare providers, as well as the public, need to be aware of local and state laws, especially about adolescents having a say in their medical decision-making and goals/limitations of care. Also, the 18- to 21-year-olds who are either neurologically devastated or have the developmental age of a young child need to have advocates who understand the law (individual states may differ) and have their best interests in mind at all times when making decisions about their EOL care.[22]

Children with complex chronic conditions often have frequent life-threatening events and acute illnesses. Advanced technology and treatments have helped children survive these events, making care, decision-making, and instituting limitations more difficult for both providers and patients/families. Common thought becomes, "if the child survived the last life-threatening event, therefore he will survive the next." As a result, another barrier has emerged over the years: death is seen as a failure of the healthcare system and not a natural process of the illness/disease.[22] Advocates for PPC recognize that advanced technology/treatment saves lives, but fear it may cloud decision-making and prolong suffering.

Pain and symptom management also have become more complex and challenging. Children with complex conditions often end up on multiple medications and/or treatment modalities, making it harder to cross-check interactions and determine doses and effectiveness. Primary care providers lack expertise due to limited experience with these complex patients and therefore shy away from caring for them. Hospice agencies tend to feel their expertise in EOL care is insufficient in caring for the complex pediatric patient. Provider education and ongoing support from palliative care colleagues help diffuse some of the anxiety in caring for these children and therefore should optimally remain an integral part of caring for children and families within the context of PPC.

Last, the cost of caring for children with chronic life-limiting illnesses/conditions has been a barrier to pursuing pediatric hospice. Pediatric hospice or palliative care typically requires longer, more frequent home visits; longer time for family meetings and decision-making; more coordination of care with multiple physicians, other providers, and insurance companies; visits to schools by members of the team on behalf of the sick child or siblings; and hiring or access to pediatric experienced nurses, social workers, and child life specialists and aides. Ongoing therapies for palliation of distressing symptoms, including blood transfusions, antibiotics, chemotherapy, and enteral and gavage feedings, typically continue longer for children than for adults. The cost and responsibility for covering these therapies may be an additional factor for home-based providers in deciding whether to serve children. Now with concurrent care and Medicaid waiver programs, this barrier is being addressed and will hopefully become less of an issue as implementation becomes more uniform and consistent across healthcare settings.

Nursing Considerations

Nurses providing PPC and EOL care often experience emotional pain and suffering themselves related to their young patients' declining conditions and poor prognoses. In programs where nurses are not clinically trained or emotionally prepared to manage pediatric patients, many issues can emerge as a result of their anguish. Previous losses of a similar nature, unresolved grief issues, conflicting beliefs regarding "supportive care-only" interventions, and insecurities and self-doubt are all common, even within the hospice setting. Personal and ethical dilemmas can emerge regarding withdrawal of aggressive care or nutritional support. Interdisciplinary ethics consultations can bring an invaluable contribution to the decision-making process and often raise the option of a PPC consult or referral to hospice care. Nurses working in predominantly adult-oriented care settings may lack pediatric physical assessment and symptom management skills, as well as knowledge of the diverse disease processes and developmental stages and related needs essential to care for neonatal, pediatric, or adolescent patients. Those with a background in aggressive and curative care may find it difficult to support a family in transition to a palliative focus of care. It is not enough to just provide education; they need ongoing mentoring, opportunities to process and get feedback on outcomes, interventions, communication, and real-time direction from experienced palliative care nurses and others.

Hospices, palliative care teams, and hospital inpatient teams should always consider and remember that nurses have the most frequent and direct contact with patients and families. They are the clinicians who provide ongoing care and education and are often the ones present during the child's death. Their support and clinical care has a high potential to greatly affect the entire experience that the family will reflect on for the rest of their lives. Nurses who are trained properly can and do report feeling honored and privileged to help patients and families during one of their most painful, private, and intimate experiences. They find it rewarding to know they were able to provide support through such a difficult experience by simply acknowledging and respecting their patient and the family's pain and grief. Therefore, the better prepared, supported, and educated nurses are, the better chance they have to help influence a more positive and less traumatizing experience for all involved.[23]

Respecting What Parents Want and Need from Their Healthcare Providers

Nurses can support parents and families in the hospital and at home by identifying their concerns and fears regarding things such as routine care in the hospital, life outside the security of the hospital, what to expect at home, how to handle emergencies, and knowing when to call for help. Nurses have an important role in creating plans for how they will communicate with the family and in helping families anticipate what may happen in different situations, as well as having appropriate medications, resources, and contacts in place when needed. In the home setting, it may be helpful to think of parents as "first responders," and, as such, they require adequate access to what is needed to respond best to their child's issue when it arises. For example, having an "emergency kit" with a few basic medications in one or two doses for common crisis situations can prevent needless fear and suffering until a home care nurse arrives. Educating parents as thoroughly as possible for transitions in care and settings will reduce anxiety and unnecessary problems faced at home.

Imagine how overwhelmed parents must feel when their child is diagnosed with a serious illness. Nurses' goals are to help parents and children feel confident and competent in the hospital setting and at home, to feel cared for and connected to their care team, to be respected in how their cultural and religious or spiritual beliefs influence decision-making and provision of care, and to preserve hope. Parents also desire to remain in the role of parent to their child and may want to have control over time, routines, and ritualizing care to make their child feel safe and comfortable. They want to have their child recognized as unique and special and have some semblance of "normalcy" and intimacy allowed in the framework of their existence, whether at home or in a facility. Discussing the role and impact on siblings and/or others at home is necessary on an ongoing basis, and support for other family members may be an essential part of care. The communication between professionals and parents and children throughout the time of illness and at the end of life must be grounded in caring and compassionate relationships and mutual trust. PPC places special demands on healthcare providers, not the least of which is an obligation to nurture relationships that can hold both vulnerability and suffering within their embrace.[24]

Intrinsic to the adaptation of pediatric-specific palliative care is that care is firmly anchored in developmental standards and that pertinent modifications are made to care based on the individual child's cognitive, emotional, physical, and spiritual development. The NHPCO launched an effort to create pediatric-specific hospice standards to guide programs and direct how care is rendered, regardless of whether care is delivered in the home, hospital, or long-term care or respite facility.[11] Box 59.1 was created to serve as a pediatric-specific appendix to the existing NHPCO Standards of Practice for Hospice.[11]

General Considerations for Pediatric Palliative and Hospice Care

As described in detail earlier, PPC is an approach to care for children living with life-threatening illness and for their families, one that aims to improve QOL along a physical, psychological, social, emotional, and spiritual continuum and is best delivered through the collective efforts of an IDT that includes the child and the family as the center of care.

Essential components of interdisciplinary PPC include, but are not limited to:

- Enhancement and promotion of QOL
- Respect for the uniqueness of each child and family
- Care that is introduced early and remains in place in conjunction with other therapies/treatments
- Care plans based on goals that reflect the child's and family's values and preferences
- Integration of physical, psychological, spiritual, emotional, and social aspects of care
- Coordinated care provided by an IDT that includes the child's primary team
- Relationships based on trust and mutual respect between child, family, and IDT members
- Effective management of pain and other symptoms
- Use of effective communication strategies
- Care that involves community support (i.e., schools, places of worship, community groups/teams)
- Inpatient and outpatient hospice support and services
- Anticipatory guidance and bereavement support[25]

The essential elements of PPC (see Figure 59.1),[26] which will be reviewed in more detail later, need to be woven into every aspect of nursing care, with consideration given to how each component of care will affect each child's and family member's daily life, as well as their lives over time.

Addressing the Particular Needs of Children and Families

The philosophy of palliative care for children is similar to that for adults; however, the practical elements of palliative care differ in many ways when providing this type of care for children. Clinicians providing PPC must not only learn the nuances inherent to this type of care, but must also pay particular attention to the specific needs of children and families as they assist them through their illness experience and death. One must consider the reality of the burdens placed on families when caring for children with life-threatening illnesses and how their entire existence can center on details of medication schedules, treatment plans, medical appointments and trips to the hospital, and the minutiae of providing constant care, leaving little time or energy for anyone or anything else. Taking these elements into consideration, it is the responsibility of interdisciplinary PPC providers to create individualized plans of care that are consistent with the goal of maintaining "normalcy" as much as possible while simultaneously adjusting to the "new normal" that families are often challenged to embrace. In these situations, one must consider the support and guidance that families will need when the focus of care changes as the end of life draws near. Nurses have a crucial role in supporting families through their fears and frustrations along with normalizing the full range of feelings that may ebb and flow throughout the course of a child's illness and death.

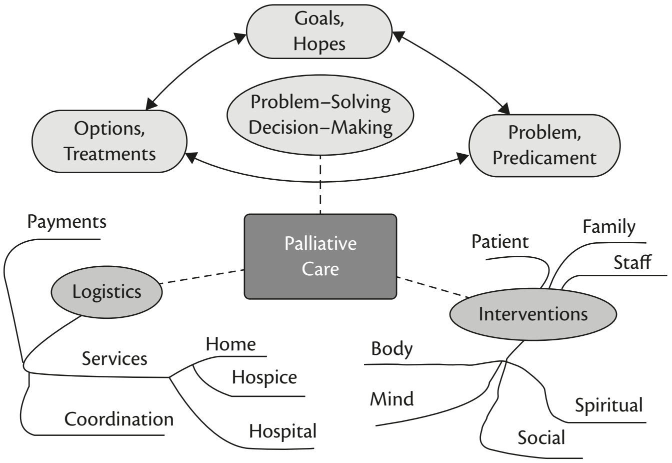

Figure 59.1 Essential elements in pediatric palliative care.
Source: Reference 26.

The Team

As mentioned earlier, it is widely recognized that PPC is best delivered using an interdisciplinary approach, although the make-up of inpatient PPC teams will vary depending on available resources. Common members of interdisciplinary PPC teams include physicians, nurse practitioners, nurse coordinators, social workers, chaplains, child life specialists, therapists from different disciplines (such as art and music), bereavement coordinators, and/or psychologists. Members of an interdisciplinary PPC team are professionals who have received specialized education and preparation for the care of children and families living with life-threatening illness and can serve as good resources for other allied professionals (i.e., psychiatrists, psychologists, representatives from other consulting services, primary care providers, other therapists—physical, occupational, respiratory, community representatives—teachers, coaches, religious leaders, hospice team members) who are also part of a child's care team. Together, they can provide comprehensive care for children and families, while nurses and APRNs may serve as coordinators of such interdisciplinary care as well as liaisons between the child, family, and team. Collectively, it is the role of the IDT to accompany the child and family throughout illness, death, and bereavement and to support families in coping with the challenges of living with a life-limiting illness and the suffering that may come along with it (Figure 59.1).[27]

An interdisciplinary approach to care should include optimal communication focused on patients' and families' goals of care, symptom management, and psychosocial support while relieving suffering, ensuring comprehension, and maintaining a sense of collaboration between the providers and patients/families.[28] Clinicians must be willing to listen and empathize as they build trust with families because trust and mutual respect serve as the foundation for positive and successful interactions between members of the IDT and the child and family. This interdisciplinary system of care can be defined as complex and adaptive because of the diversity among the various professionals on the team. Positive patient, family, and provider experiences can evolve from having a common goal and how well members relate to and interact with each other while maintaining a holistic approach to care, including trust and respect for one another and the patient's and family's autonomy.[29]

Family-Centered Care

In essence, palliative care considers the patient and family as a unique entity whose members all require care.[22] When a child is diagnosed with a life-threatening condition, the entire family, whomever that may include, is affected both on an individual and a collective level.[28] Special attention should be paid to the role of each person in the family and to how those roles may change throughout the course of a child's illness; thus, understanding existing and evolving relationships among family members is extremely important. Understanding the meaning of the illness and/or death experience must also be considered within the historical, cultural, spiritual, and environmental context of each family.[28] See Table 59.1[30] for guidelines for children's developmental understanding of death. Please refer to Chapter 32 for more information on supporting families in palliative care.

Support for Parents/Guardians

Families often describe their experiences of living with a child with a life-threatening illness as "being on a roller coaster." From the first time a parent senses something is wrong until the time of death, parents are faced with the myriad stressors associated with daily life/providing care, making difficult decisions, and often feelings of anger, sadness, disbelief, and withdrawal.[28] Parents and other family members will have needs that range from needing to understand their child's diagnosis and illness course to working through the different emotional experiences, integrating a sense of meaning (spiritually) from the experience, and requiring support for issues regarding housing, finances, childcare, and work.[28] Parents may feel as if they are losing control over several aspects of their lives, and it is therefore helpful for nurses and other members of the IDT to find ways to continually allow parents to remain in control, for example, by involving them in planning the child's daily routine, allowing them to participate in care, and asking if there is a certain way they would like things done. The need to feel a sense of control is also relevant to the sick child who may be

Table 59.1 Developmental stages and perceptions of death

Age	Basic conflict	View of death	Suggestions
Birth–18 months	Trust vs. mistrust	No sense of finality; death is viewed as continuous with life, child is reactive to the stress.	Use simple physical communication and provide comforting and nurturing care.
Early childhood: 2–3 years	Autonomy vs. shame and doubt	Death is seen as reversible and not final; the child may feel that death is a punishment. Children may feel that they are responsible for death.	Expect regression, clinging, or aggressive behavior. Encourage expression, as the child may be concerned about family function after a member dies. Use honest and clear language to explain death and dying.
Preschool: 3–5 years	Initiative vs. guilt	Death continues to be understood as temporary. The child may have a literal understanding of death and will respond with curiosity and questioning.	Open communication with clear language should continue to be utilized. The child should be encouraged to ask questions about death and dying.
School age: 6–11 years	Industry vs. inferiority	Death is understood as permanent, and the child understands that the body does not function (no breathing, heart stops beating). The child may also feel responsible and guilty for the illness. The child may have spiritual ideas about afterlife. The child may not want to discuss feelings.	Reassure the child that death is not their fault. Aim to maintain as normal a structure as possible. Include the child in after-life plans (funeral planning, last wishes).
Adolescence: 12–18 years	Identity vs. role confusion	Adolescents understand the finality of death and may develop a mature understanding of death. They may try to take responsibility for adult concerns within the family (such as finances and caretaking). Feelings of anger may be present.	Allow time for the child to reflect. Listen to concerns and questions. Support efforts for autonomy and control.

Source: From Reference 10.

fearful from experiencing many physical and emotional changes. Nurses can assist parents with methods to help themselves and their child feel in control regarding aspects of their experience. Things such as establishing a daily routine; having children participate in conversations about care, when appropriate; and knowing what side effects to anticipate from medications, treatments, and therapies is empowering and fosters an environment of mutual trust and respect.

Support for Siblings

Caring for the entire family is an essential component of palliative care. Along with parents' needs, siblings' unique needs must also be considered when caring for a child and family living with life-threatening illness. Parents may find it difficult to provide support for both their sick child and their other children due to the controlling nature of the needs of a child with a serious or life-threatening illness. For this reason, caregivers and healthcare providers must pay close attention to the siblings for signs and symptoms of emotional distress and then identify strategies and resources to support their needs accordingly.[31]

Strategies for engaging with siblings may be as simple as including siblings during visits (e.g., greeting them by name first when entering a room), asking about their favorite toys or interests, or participating in a small activity together during a home visit. It is important to repeatedly evaluate the well child's level of understanding about the sibling's condition. Family meetings are also a good setting in which to discuss how everyone is doing (including sick and well siblings), how they each perceive the situation, how their needs are/are not being met, and how their fears and concerns can be addressed. Hospice and hospital volunteers, art therapists, and child life specialists are also extremely helpful for activities specifically with siblings such as picnics, outside play, reading stories, or memory-making activities such as handprints/molds, "memory boxes" to store keepsakes, memory beads, and/or picture collages. The goal for siblings of terminally ill children is to enhance their feelings of involvement from the time of diagnosis to the greatest degree possible to facilitate a healthy adjustment and eventual grieving process.

Interaction with Schools

In addition to family members, multiple professionals are involved in the care of children living with life-threatening illnesses and are committed to maintaining their QOL. Children living with complex chronic and/or life-threatening illnesses may also have an IDT of caretakers at school, including teachers, healthcare providers, and a range of therapists (e.g., occupational, speech and language, physical). Because children spend significant time at school, school personnel are intimately involved in helping meet their various educational, therapeutic, medical, and basic care needs (i.e., feeding, toileting, hygiene) and play a fundamental role in advocating for them. Families often develop supportive relationships with members of their children's school-based care teams and rely on them for support and guidance as they face different care choices throughout their children's lives, as well as for responsible execution of care plans to meet children's individual needs. Thus, it is essential to keep school team members informed of any choices that families make, especially if those decisions impact the care provided to the child at school, and to include the school team in decision-making conversations. It is also important and helpful to provide education, support, and resources to members of the school team, as well as to children's classmates and/or their family members, whenever possible.

Components of Care

This section will address some of the essential components of effective PPC. Each section is meant to give a brief overview and explain why the topic is important or relative to comprehensive palliative care. Because these topics will be reviewed in greater detail in other chapters of this text, the following sections are not meant to provide an exhaustive explanation or to be all-inclusive regarding all aspects of how to provide such care.

Communication

> Let us communicate with each other clearly, compassionately, and collaboratively, as we strive to improve the quality of life for children including, when necessary, that part of life that is dying.[26(p. 583)]

Good communication is the cornerstone of palliative care and serves as the foundation for building and maintaining relationships with families and other team members. Communication serves several purposes, among which are providing and gathering information, expressing sensitivity and/or empathy, and building partnerships. Having conversations with families about goals of care as early as possible has been shown to reduce suffering.[10] Effective communication considers everyone's needs, including all family members and children, and allows for an open exchange of information and flow of emotions.[32] It involves the use of verbal and nonverbal cues, and thus it is important to pay attention to subtle cues that may be offered by both children and adult family members. In pediatrics, it is important to ask families whether and how they would like to include their child in discussions, and it is also essential to consider the child's chronological and developmental age. Effective communication is a skill that must be learned and can be developed over time by all healthcare team members so that all palliative interactions with children, families, and other healthcare team members facilitate the development of trust and allow children and families the opportunity to ask questions and engage in a healthy, honest dialogue with their healthcare team.[33]

Please see Chapter 5 for more information on the essential components of communication.

Pain and Symptom Management

Pain and symptom management is another essential component of comprehensive and effective PPC as no parent or healthcare provider wishes for children to suffer unnecessarily. Some hospitals have separate pain teams, and many primary teams will manage children's pain and symptoms independently; however, the PPC team may be consulted to recommend a plan, and it is important for nurses to be familiar with general principles of pain and symptom management in regard to PPC. It is also important to recognize that there is often reluctance to manage pain aggressively in children based on myths and societal, cultural, religious, and familial beliefs that may make parents/guardians leery of opioid use to treat pain, such as the fear of "giving up" on their children, along with the notion that opioids may be "too strong" or that their children will become addicted. Healthcare providers' reluctance may stem from significant gaps in the existing evidence base; lack of sufficient education regarding pain management[34];

and misconceptions about opioids, such as frequency and severity of side effects, shortened life expectancy, and increased tolerance leading to difficulty managing pain at the end of life. Being aware of these hesitancies is helpful so that fears can be addressed and healthcare team members and family members can be educated about the realities of pain management in children with life-threatening illness and at the end of life.

Aside from pain, there are three other categories of symptoms that are known to be the most distressing to children and families receiving PPC: dyspnea, gastrointestinal disturbances, and neurological changes.[10] Adequate symptom control is a necessary part of effective PPC, and assessment and treatment of symptoms should be done in the least invasive way possible and should not contribute to more distress and/or suffering.[10] Gastrointestinal disturbances, including nausea, vomiting, decreased appetite, and constipation, are common in children with chronic and advanced illness, and identifying and treating the underlying cause,[10] using both pharmacological and nonpharmacological techniques, is a necessary part of care.

Many of the symptoms experienced, as well as the principles and medications used for pain and symptom management, are similar in adult and pediatric palliative care. The differences stem from the age- and developmentally appropriate assessment of pain and symptoms and from dosing medications, as pediatric doses are based on children's weight. Detailed and repeated assessment of children's pain or other symptoms is a crucial first step toward effective management. This includes a thorough evaluation and history, a detailed assessment, and a physical exam, as well as pharmacological and integrative management of pain.[34] It is also important to recognize that a child may be playing or sleeping and not appear to be in pain, but that does not mean that he or she isn't experiencing pain. Many excellent resources are available to nurses for gaining competence in pain and symptom management for children, and nurses who care for children over time will become adept at recognizing when children are in pain or are uncomfortable. In addition, families require practical help, information, explanations, and support. Attention must be paid to the practical issues of preparing for pediatric-appropriate supplies, medications, formulas, feeding tubes, medical equipment, documentation, and teaching tools for parents and children. Ongoing support and education for children and families is an essential part of delivering effective PPC.

Please see Chapters 8 and 9 for more information on the essential components of symptom and pain management in PPC.

Psychological, Emotional, Social, Religious, Spiritual, and Cultural Care

Pediatric palliative care is best delivered by an IDT, including individuals who can provide psychological, social, emotional, and spiritual support, such as psychiatrists, psychologists, social workers, and chaplains; however, it is important to recognize that all members of the team are also an integral part of providing this type of support to families. Colleagues from psychiatry and/or psychology should be consulted to fully assess concerns for psychological and/or emotional distress. Although there are no validated assessment tools to gauge the precise social and emotional needs of children and families, careful assessment should be conducted regarding the child's and family's developmental level and ability to complete developmental tasks; the experience of emotional symptoms; practical factors such as financial status, living situation, and social support; and religious or spiritual/existential background, preferences, beliefs, rituals, and practices.[33] Thus any comprehensive palliative care assessment and plan should include conversations and activities that explore all of these aspects of children's and families' lives. See Table 59.2 for examples of open-ended questions and behaviors to observe when assessing psychosocial concerns and strengths in children receiving palliative care and in their families.[33]

Psychological Symptoms and Suffering

It is essential to recognize that the experience of caring for a child with a life-threatening illness may cause increased psychological and emotional distress for family members as the illness progresses and the level of care needed increases. For example, the extended time required to provide physical care for affected children may result in increased energy expenditure by parents and the feeling that the time and energy necessary for other family responsibilities (e.g., other siblings) and activities (e.g., work, community activities, etc.) are being depleted. This can also be accompanied by a sense of guilt. It is important for the IDT to recognize the stresses that families endure and talk with them about this routinely. It is also important to be aware that while worry and sadness are natural in the context of having or caring for a child with a serious illness, increasing frequency of these symptoms or significant impairment in functioning are signs that the individual and/or family should be evaluated by a mental health clinician.[35]

Thus, it is appropriate for families and children to be offered early psychological and psychiatric consultations to assess the intensity of potential emotional distress, especially given that the symptoms of anxiety and depression are common, treatable, and associated with distress and morbidity, yet are often unrecognized and undertreated in this population.[36] Also, it is essential to offer resources for coping (via social workers, chaplains, psychologists, etc.) in an attempt to support the best functioning possible for the child and family members.[37] Consultations may facilitate open discussions, relationship-building, and survival strategies that may help to offset the emotional distress experienced by family members. Effective strategies should help equip affected children and their family members with constructive coping mechanisms (e.g., self-care activities, relaxation exercises, yoga, meditation or prayer, memory-making, journal writing, expanding or enlisting community resources, reframing cognitive distortions, or limiting catastrophic thinking, etc.). Also, strategies offered by healthcare providers may enable family members to plan effectively for the future when the child's prognosis is unclear and if the child's life span may be limited.[38]

Anxiety and depression are forms of suffering commonly experienced by children with chronic or life-threatening illnesses and can also encumber the primary caregivers of the child as well as other family members, friends, and siblings. While there are clear differences in the treatments for anxiety and depression, both disorders/states are treatable with nonpharmacological methods such as cognitive-behavioral techniques that can be used quite easily by affected children and adults, as well as with medications in conjunction with talk therapy. Examples of nonpharmacological methods include guided imagery, use of relaxation and breathing exercises, meditation, reframing automatic negative thoughts, and hypnotherapy (which children can learn to do themselves). Complimentary medical therapies such as physical massage,

Table 59.2 Examples of open-ended questions and behaviors to observe when assessing psychosocial concerns and strengths in children receiving palliative care and their families

Area being assessed	Open-ended questions	Patient behaviors to observe	Parent behaviors to observe
Developmental appropriateness and understanding	Tell me about what is happening with your treatment. What questions do you have that you have been too shy/too scared to ask? Why do you think this is happening to you? (Same questions can be asked of parents)	Indications of fearing sleep (will not go to sleep, resists sedative medication) Indications of fear of separation Degree to which patient can enjoy some developmentally appropriate activities (artwork, talking to peers, planning fun activities)	Coddling an older child Apparent discord between treatment of child and child's developmental level Ability to let child explore some developmentally appropriate activities Ability to effectively soothe/nurture or comfort the child
Beliefs about pain	What do you think is happening now that is making you hurt? How worried do you get when you feel pain? What do you worry about? What do you like (or not like) about using your pain meds? What concerns do you have about using your patient-controlled analgesia? (Same questions can be asked of parents)	Use of a range of physical behaviors to demonstrate different levels of pain Behavioral manifestations of anxiety with increased pain Over- or underuse of pain medications	Degree of own distress or focus on child's daily pain experience Ability to comfort and reassure the child Ability to distract the child from pain and engage in other activities
Emotional issues	How are you feeling? What are the things you are sad about? What are you missing because you are sick? What are you worried about?	Sadness, apathy Lethargy Unwillingness to engage in activities or conversation (must rule out physical causes for these symptoms)	Hypervigilance over child's pain, labs, or physical condition Signs of anxiety or excess sadness Avoidance of discussing important issues or of seeing the child or physician Asking same questions over and over again of the medical team
Communication	Sometimes it's hard to talk about some medical things. Who can you talk to about the hardest things? What things would you like to talk or hear about, but haven't been able to find someone to listen or talk to? What opportunities are people offering you to talk, and how does it work if you tell them you don't feel like talking?	Patient asking questions about death, dying, prognosis, or related issues Patient becoming annoyed when people "push" him or her to talk	Reluctance to talk to child or to be alone with him or her Eager insistence that child needs to talk despite child indicating need not to talk Expressing anger or exaggerated conflicts regarding the medical care
Practical issues	To parents: How have the extra medical expenses and any lost income you may have experienced affected your family? How do you get to the hospital for visits? What meals do you eat when here? Who is caring for members of the family still at home? Who lives at home? Who cares for your child when he or she is not in the hospital? What space is available in your home for hospital equipment? What would it be like for your family to have home care nursing in the house?	Missed appointments Frequently bouncing back to the hospital after discharge Desire to want to stay in the hospital despite being medically cleared to go home Strong desire to have no medical intervention (including equipment or home care staff) at home	Same as child observations

(continued)

Table 59.2 Continued

Area being assessed	Open-ended questions	Patient behaviors to observe	Parent behaviors to observe
Spiritual needs	What religious group, if any, do you belong to? What help would you like in thinking about religious or spiritual issues? What does your family believe about what happens after death? What traditions or rituals does your family practice when someone is sick or dying? What support from the hospital would be most helpful to you?	Confusion or distress regarding afterlife issues Worries about what kind of service to have Unusual behaviors that may be explained or understood as cultural rituals around illness or death	Same as child observations

Source: From Reference 33.

acupuncture, biofeedback, Reiki, and aromatherapy can also be extremely helpful in reducing the symptoms of anxiety and depression. Pharmacological treatment would be prescribed by a psychiatrist consulting with the primary team. As mentioned previously, it is imperative for healthcare providers to regularly monitor for the presence of psychological distress among children and family members over time and to consult clinical colleagues who are trained to properly assess, diagnose, and provide treatment plans for patients or families struggling with anxiety and depression.[38]

Social Aspects

Practical factors in a child's and family's life can have a direct impact on physical as well as psychological symptoms and treatment. Things such as family constellation, financial resources and constraints, employment status, healthcare benefits, childcare, transportation, and the ability to manage the myriad practical demands of living with and caring for a child with a life-threatening illness should be considered.[33] Social workers are usually the members of the IDT most prepared to assess these factors and to identify and connect families with the appropriate resources.

Religious/Spiritual and Cultural Considerations

Another integral part of providing PPC is an understanding of children's and families' spiritual, religious, and cultural beliefs and how these beliefs influence the decisions that they make,[33] and addressing spiritual needs of children and families is an important component of palliative care nursing. Families will often have their own ways to express their beliefs—some will consider themselves "religious" and partake in traditional rites and rituals; others may say "spiritual" and tend to have more universal beliefs not rooted in specific practices,[39] and others may not find it helpful to discuss their beliefs in terms of a structured or identified system of belief. Regardless, it is necessary for members of the PPC IDT to conduct spiritual assessments with families in a variety of ways because parents of children with serious illness believe that religious or spiritual beliefs are important factors in their coping efforts and decision-making.[33] Chaplains serve to address spiritual suffering, improve family–team communication, and provide rituals that families may request, such as ceremonies or sacraments.[40] Although matters of faith are often discussed with chaplains, any member of the PPC IDT should have some level of comfort in giving families the space they need to talk about religious and spiritual beliefs, practices, and values. Having these types of discussions may be considered one of the most challenging parts of PPC, but these same discussions may also be what allows both family members and clinicians to remain grounded and to maintain a sense of normalcy.[41] It is therefore important for PPC teams to be open to such discussions and to be aware of and utilize available hospital- and community-based pastoral care services.[33]

Table 59.2 provides examples of some open-ended questions to use and behaviors to observe when assessing psychosocial concerns and strengths in children and families and serves as a guideline for having conversations about such topics.[33]

Talking to families about their cultural and ethnic beliefs, customs, and practices is also important and may or may not be tied into their religious or spiritual beliefs. Of note, using a certified interpreter (i.e., not a family member or other staff member) may be necessary and should not be overlooked when children and families do not speak English, even if they say they understand what is being said. Various cultures approach children with life-threatening illnesses differently and have different beliefs and practices or rituals surrounding illness and/or death. It may be unacceptable to speak about illness or death or to discuss medical information in front of children. Nurses and other members of the healthcare team cannot be expected to be familiar with customs from every cultural background, and assuming a posture of humble curiosity is welcomed by individuals of other cultures when one does not know the culture and customs in depth. It should also not be assumed that just because someone comes from a particular cultural or ethnic background that he or she subscribes to the particular beliefs and practices from that group; thus, it is always important to ask children and families about their personal preferences.

Preserving Hope

A common characteristic of children living with life-threatening illness and their families is a prevailing and powerful experience of hope, evidenced in their language and decision-making. It is important to preserve and nurture hope during all stages of the child's illness. No matter how grim the situation, one should always strive to deal with matters in a positive, yet realistic, manner, taking the lead from the child and family. The focus of hope may change over time; for example, from hope for cure to hope for a longer remission than previously, to hope that the child can continue to be cared for at home, or to hope that the child will die without pain. Hope may also be centered on a child-specific wish, such as to return to school once more, to celebrate an important birthday, or to reach a significant milestone or rite of passage. Other expressions of hope include planning for a visit from grandparents, having friends gathered together, or even gaining the understanding for children, particularly adolescents, that their loved ones will survive and be "OK" after they die. Hope offers opportunities for growth for the child and family, yet it can also become challenging for both families and IDT members to try to balance remaining hopeful while also having realistic expectations. Thus it is important to openly discuss hopes and fears with children and family members, as well as with other members of the IDT.

Please see Chapters, 30, 34, and 35 for more information on the essential components of spirituality and hope in palliative care.

Ethical Considerations

A large part of PPC involves helping families with decision-making. Clinical ethical dilemmas are inherent to issues surrounding palliative and EOL care, and it will often be the role of the nurse and/or APRN to anticipate, recognize, define, examine, and manage ethically problematic situations[42] that arise in the care of patients and families, particularly during times of serious illness and/or at the end of life. Ethical dilemmas abound when providing such a wide array of care surrounding topics that are deeply rooted in personal, cultural, religious, and social values. Although nurses and other members of the PPC IDT are not expected to be ethicists, it is helpful to be mindful of the potential ethical dilemmas that will arise when working with families in these circumstances and to be aware of when to consult with the hospital's ethics committee when additional support is needed. It is, therefore, also the role of the nurse/APRN to recognize, contemplate, and use appropriate resources to guide such discussions and decision-making processes with patients and families.[42]

Ethical issues that are associated with EOL situations include decision-making under conditions of ambiguity, adequately informing patients and their families about treatment options, balancing QOL against extending suffering, managing intractable suffering, and futile treatments. Resources are available to help guide the decision-making process and to help children, adolescents, and adults express how they want to be treated throughout their illness and at the time of death from a medical, personal, emotional, and spiritual perspective.[43] Some helpful documents include *My Wishes* (for young children), *Voicing My Choices* (for adolescents), and *Five Wishes* (for adults) published by Aging with Dignity and available at www.aging-withdignity.org.[44] This section does not serve to provide an all-inclusive discussion of ethics in PPC, but rather to highlight some of the dilemmas nurses may face. Please see other chapters in this text for a more thorough discussion of ethical considerations and EOL decision-making, such as Chapter 61.

Perinatal Palliative Care

Perinatal palliative care is a unique component of PPC that is expanding rapidly as an increasing number of expecting parents receive diagnoses of life-limiting fetal conditions (LLFC) during pregnancy.[45] Many families are faced with difficult decisions that need to be made shortly after birth and, in some instances, even before a child is born; therefore, it is necessary to recognize the unique need for palliative care in the perinatal and neonatal period. The model for perinatal palliative care has become internationally recognized and is often introduced during pregnancy. Nurses play a unique and vital role in assisting and supporting families in creating palliative care plans for pregnancy and/or birth.[45]

Perinatal palliative and hospice care is an innovative and compassionate model of support that can be offered to parents who learn during pregnancy that their baby has a fatal condition, an unfortunate situation that occurs with increasing frequency as prenatal testing advances. This unique group of parents faces the daunting challenge of anticipating and preparing for the birth *and* the possibility of death of their baby simultaneously. For parents who receive terminal prenatal diagnoses, perinatal palliative care can be instrumental in helping them make the decision that is best for their family regarding whether or not to continue the pregnancy. For families who choose to continue their pregnancies, even if the baby may die shortly after birth, perinatal hospice helps them embrace whatever life their baby might have, before and after birth. Perinatal hospice support begins at the time of diagnosis, even before the child is born. It can be thought of as "hospice in the womb," including birth planning and preliminary medical decision-making prior to birth, as well as more traditional hospice care after birth, depending on how long the child survives. With the support of perinatal palliative care, families are given the opportunity to feel some level of control by making plans for the baby's birth, life, and death based on their individual needs for supporting themselves, their other children, the grandparents, and friends.[46] It also provides families the opportunity to honor their baby in a way that is meaningful to them and helps families participate in memory-making experiences. Strengthening this experience during this time may help diminish long-term psychological implications for parents and siblings.

Perinatal hospice is not a place. Ideally, it is a comprehensive team approach that includes obstetricians, perinatologists, labor and delivery nurses, neonatologists, neonatal intensive care unit (NICU) staff, chaplains/pastors, and social workers as well as genetic counselors, therapists, and traditional hospice professionals. Perinatal hospice is a beautiful and practical response to some of the most heartbreaking challenges of prenatal testing.[47] Some programs exist within a hospital setting, such as the labor and delivery unit, NICU, and maternal and child areas. Other times, it presides within community settings. It naturally creates a seamless continuum of care across settings (office to inpatient to home) and providers and includes advanced decision-making within the framework of a "birth plan," which includes the "who, what, when, and where" for the delivery and beyond.[45] Perinatal palliative care may naturally extend into neonatal palliative care, as some infants will live anywhere from days to months to years after birth.

Please see Chapter 62 for more information on the essential components of neonatal palliative care.

Care at the Time of Death

Nothing can fully prepare families for the final moments of their loved ones' lives and the precise time of death, but there is much that can be done to help families anticipate what to expect so as to avoid unnecessary surprises when the time comes. Conversations about such sensitive topics may feel difficult to initiate, but parents are often wondering about these things and may be afraid to ask. Thus, initiating the conversation after a relationship has been established and at a time that feels appropriate is essential. Families should be reminded that PPC clinicians cannot predict exactly when and how death will occur as it can be different for everyone, but parents and family members should be prepared for the possible range of changes that can happen, along with when they might expect such changes and what things may look like, feel like, sound like, smell like, and so forth. Consider all the senses for both the adults and any other children who will be present. Parents also may appreciate written handouts in language that is not too clinical or frightening so that they have them to review at a time when they feel ready to do so. Having such knowledge may also prepare parents to talk with each other, other children, and family members. Families may have memories from previous experiences of death of other family members and may conjure images or memories from that time that may or may not be helpful, depending on what the particular experience was like for them.

Children and family members will likely have fears associated with death and the dying process. This may include fears about what dramatic events can unfold, fear of being alone at time of death, fear of a loved one missing the death, and fear of being unprepared for an unexpected emergency. Understanding the physical progression of events and the nearing-death awareness that is common among children and adolescents may be reassuring for both members of the team and the family. It is essential to review goals for the time of death well before the time comes so that families feel as in control of the situation as possible. For example, children and families likely will have an idea of where they would like for the final hours or days of life to occur, and, when possible, nurses and other members of the IDT can try to align the proper resources to allow this to happen. If families desire to remain in the hospital, they should be given a private space or room to be together as a family. Several children's hospitals allocate a specific room or space, often called a "comfort corner" where children may be moved to spend their final hours together with their family. Typically, changing locations close to EOL is not desired; however, for some families, it may be very important to make it home from the hospital or to get to the hospital in the event of an emergency before death. Thus it is again important to talk with families about their wishes for this time. It is also crucial to consider whom a family may want to be present. In most instances, family members will be called to visit as the time of death nears, and the child's bedside, whether in the hospital or at home, can become the gravitational force for loved ones to gather. Families may also have particular wishes about who should be present at the actual moment of death, as sometimes parents want to be alone with their child, with or without other children being present. Other times, families may choose to get in bed with their child. The tenderness and intimacy of these final moments is beyond description, and being present at this time with a family is a very precious privilege for everyone involved in the child's care, especially nurses who often spend the most time at the bedside.

Creating a Sacred Space

When a child is dying, regardless of his or her age, the very space becomes sacred ground, and it is important to maintain the holiness of that space immediately following the death, if only for a brief period of time. This also allows for a brief pause to honor the nurse's role in maintaining the dignity of a child and his or her family surrounding death before moving on to the next task. Some programs place a special sign on the door, or an image of a dove, butterfly, flower, or leaf to subtly designate this sacred space and to minimize interruptions in and out of the room during this time. Honoring and respecting the space also models to staff that it is not just "business as usual," at least for a brief time. If a child dies at home, some families may choose to have the child remain in their bed or keep the space intact for a short time before having the body removed. Other families may desire the prompt removal of their child's body, which is a personal decision that should also be respected. Cultural and religious practices may guide what happens at time of death and immediately following, but generally time is allowed for bathing, dressing, holding or rocking the child, offering prayers, obtaining handprints (if not obtained before), cutting a lock of hair, and gathering the clothing items that may have the child's scent on them (to be preserved in a timely manner in a zipper bag). Families may or may not choose to partake in these activities. Some families may wish to accompany their child's body to the morgue, if the child dies in the hospital and hospital policy allows for this to happen, or out of the house if the child dies at home. Siblings and parents or others may choose to send along a note or a little something with the child's body as a symbolic way to remain connected while apart, and sometimes children may have previously stated their wishes about what objects they would like to keep with them. It is also important to recognize that some families may choose to consider organ donation or autopsy, which ideally should be discussed with families before the time of death. Hospitals usually have programs that require that the option for organ donation be presented to families, and procedures are in place for representatives from the appropriate organizations to be notified near or at the time of death to have these discussions with families. If families elect to donate organs or have an autopsy performed, timing will be of the essence, and members of the team and the nurse should be aware of what needs to happen within what time frame to ensure that a family's wishes are met appropriately.

Self-Care

It is also important to recognize that the team members caring for the child and family will need support before, during, and following the time of death. The nurses present with the family will likely have other tasks to move on to, but it is very important to have support available to allow for at least a brief respite, break, or time away from the immediate setting. In some instances, nurses may be given a lighter caseload or, when possible, have time to debrief with another colleague, chaplain, or member of the PPC IDT both immediately following and/or at a period after the death has occurred. Great wisdom can be shared, burdens lessened, and insights and renewal gained from the time spent debriefing clinically as well as through other efforts to support colleagues. It takes a lot of energy to care for seriously ill children and members of their family physically as well as emotionally and psychologically. Preserving the meaning of and sustaining this type of work requires self-discipline and intentionality to tend to one's own centering practices and methods of self-care, whether physical, spiritual, and/or emotional. Some coping strategies may be personally beneficial, such as self-reflection and self-care, even for a few minutes throughout the day, along with building in time for ongoing renewal and reflection outside of work. Time spent focusing on other activities completely unrelated to work and taking breaks from work on a regularly scheduled basis (i.e., vacations and time with friends and family) are necessary in order to sustain this type of intense and rewarding work.[16] Also important is professional support, as many team members find relationships with colleagues in PPC to be especially supportive because no one else quite understands the emotional stressors of the work. The burden and grief experienced from caring for children with life-threatening illness and their families can be intense and serious and requires formal and informal support to prevent burnout and to cope effectively with the challenges of this work.[16]

Anticipatory Grief and Bereavement

Chapter 63 is devoted entirely to grief and bereavement in PPC, and thus it will not be discussed at length in this chapter. It would be remiss, however, to not mention the importance of anticipatory grief, grief surrounding death, and bereavement. Children and families will often begin the process of anticipatory grief at the time of diagnosis, and it is helpful for PPC team members to talk with children and families continually about the ongoing losses they are experiencing. Grief continues through and beyond the time of death, and families, community members, and team members who cared for the child and family will need ongoing bereavement support. Many hospitals have at least annual ceremonial remembrance services that families and team members find helpful for honoring and remembering the children who have died.

Overview of Nursing Care Issues for Pediatric Palliative Care

As evident, the responsibilities of caring for children living with life-threatening illnesses and their families are extensive and require an understanding of the interconnectedness of the myriad aspects of illness and suffering: physical, emotional/psychological, spiritual, and social. Nurses and members of the PPC IDT must assess for imbalances and indications of suffering in each of these areas to appropriately intervene and provide comprehensive and effective PPC. They must ensure that families are well-supported while also supporting each other and not allowing all of the burden to fall on one member of the team.[47] PPC nurses and other professionals may also experience pain and suffering,[24] and self-care, adequate support, and ongoing education and professional training are also essential components of delivering effective PPC.

Education and Training

Healthcare professionals face many obstacles and challenges while providing this type of intense and unique care to seriously ill children and their families, including lack of professional education and training.[24] Nurses specifically have reported perceived lack of skill in providing PPC, including inadequate knowledge and expertise, as well as fears regarding appropriate communication with families.[24] Many educational programs exist to train nurses and other healthcare professionals in various aspects of PPC, and there are a variety of ways to implement curriculum-based training on key topics inherent to caring for children with life-threatening illness and/or at the end of life. Interdisciplinary case discussions, "lunch-and-learn" sessions, journal clubs, and/or regularly scheduled community-based educational seminars can result in a commitment from nursing and other team members to work together and support each other or form committees on specific units or other areas. Funding from small educational grants may also be available to support training programs in PPC that include specific topics such as pain and symptom management, communication, addressing culture and spiritual needs, bereavement, ethics, and decision-making in PPC. Children's hospitals with emerging PPC programs are now offering more palliative care seminars, conferences, "just in time" teaching sessions, and trainings for new nurses, residents, and therapists, as well as staff debriefing sessions, as a way to educate others about PPC and to allow for professional development in this emerging field. Of note, PPC has been integrated into national nursing professional practice guidelines and standards, such as those of the Society of Pediatric Nursing.[48]

In recognizing that hospice and palliative nursing care has become a specialized area of nursing, the Hospice and Palliative Nurses Association (HPNA) was established in 1986. This membership organization relies on evidence-based research and data to assist members in delivering quality nursing care, symptom management, grief and bereavement support, guidance with difficult conversations, education, and encouragement in leadership and mentoring efforts. The HPNA supports credentialing for APRNs, RNs (adult and pediatric), licensed practical/visiting nurses (LP/VNs), nursing assistants, and administrators through the National Board for Certification of Hospice and Palliative Nurses (NBCHPN).[49]

Additionally, recognizing that nurses need specialized training in hospice and PPC, many professional associations are supporting localized efforts by co-sponsoring educational efforts with other entities. For example, End-of-Life Nursing Education Consortium (ELNEC) is a well-established and respected "train the trainer" initiative to teach nurses at all levels how to provide effective PPC, as well as how to teach this information to other nursing students and colleagues.[50] The curriculum is updated annually, and a pediatric curriculum is available that includes learning modules that highlight current practices and include cases, key references, supplemental teaching tools, and resources. A curriculum for APRNs was launched by ELNEC in 2012, which also includes pediatric-specific training modules. Although too numerous to list, there are several national professional organizations that offer specific training in both adult and pediatric palliative care for healthcare providers in all disciplines. The Center to Advance Palliative Care (CAPC) provides healthcare professionals with the tools, training, and technical assistance necessary to start and sustain palliative care programs in hospitals and other settings and includes an extensive listing of other trainings that are available on its website: http://www.capc.org. The Initiative for Pediatric Palliative Care (IPPC), sponsored by the Educational Development Center (EDC), is an interdisciplinary model of case-based experiential training offering PPC specific training events. More information and additional training materials can be found at the IPPC website: http://www.ippcweb.org/.[51] The NHPCO[7] also has a pediatric curriculum to address the ongoing demand for training for adult hospice programs to be prepared to care for children http://www.nhpco.org. In short, there are an increasing number of educational offerings and opportunities for nurses and other healthcare professionals to expand their knowledge of PPC.

The Future Unfolding for Pediatric Palliative Care

PPC is a rapidly expanding field with an increasing number of individual providers specializing in this type of care, growth of new and existing interdisciplinary care teams, and the expansion of available community resources.[10] Infants, children, adolescents, and their families are part of the continuum of PPC, and there is much to be done to support them and to advance the quality of pediatric palliative and EOL care. Each step toward increasing awareness about PPC is a step forward on behalf of the children who are dying without access to all of the resources that should be available to them and their loved ones. The future of PPC is aimed at improved recognition and increased utilization of PPC services and better reimbursement for palliative care providers.[10] Nurses who choose to care for seriously ill and dying children and their families need a significant support system to maintain the difficult and delicate task of balancing perspectives, as well as opportunities for ongoing personal and professional development. While challenging, this type of work is also humbling and rewarding, as those caring for children with life-threatening illnesses have the privilege of being a part of families' most intimate and powerful experiences, both throughout children's lives and during the time of their death.

> Her life would be told in days, rather than years, and yet, she changed the world and all who knew her forever. They had waited five years for her arrival and now they desired her departure to be a celebration. Her 6-year-old brother drew colorful pictures of his "angel sister" so he could "remember her always when she went back to heaven." In her brief life she knew what it was to be comforted, to be free of distressing physical pain, to have blessings said over her, to be cherished and not forgotten. Her parents were surrounded with the loving presence of those who had the privilege to care for them. They were deeply listened to, and had honest discussions as to their goals and preferences. What we discover is that the children are teaching us about living through their dying. An ever-enlarging circle of love and expertise so that all children whose lives are threatened or limited will live well and die gently. This is pediatric hospice and palliative care. (G. Walker, personal communication, November 5, 2017)

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CHAPTER 60

Pediatric Goals of Care

Leading through Uncertainty

Christina McDaniel and Jordan M. Desai

Key Points

- End-of-life goals of care communication requires effective communication, empathy, and active listening.
- It is critical to understand the values of the patient and family in order to enable decision-making that centers on what they consider important.
- Quality, as a metric used to help guide the decision-making of pediatric palliative care patients and their families, is bound in and to the culture of the individual family.
- Understanding parent and family perspectives is essential not only for providing care during the illness trajectory, but also in assisting families through their bereavement.
- Guiding conversations around goals to address physical, emotional, spiritual, and social needs is necessary to ensure holistic care is delivered.

Introduction

> My obstetrician asked, "What is the point of going on with a pregnancy when you know that the baby is going to die?" I was unable to formulate a coherent response. Now I can. From the moment I knew of my baby's existence, I loved her unconditionally.[1]

From the moment a family is faced with the life-limiting illness of a child, they are thrust into a stressful, perhaps devastating, new world. This world often communicates with a medical culture and language that is unfamiliar to most families. From an ethnographic perspective, the language and culture of medicine requires clinicians' fluency and essentially demands that ill children and their families learn at least some level of competency. The palliative care clinician must serve as a kind of "bicultural" figure and must have "one foot in both worlds."[2] The pediatric care clinician must consistently find ways to bridge the gap between the culture of medicine and the culture of the individual families served.

When asked to reflect on his rotation with a local hospice, a general pediatrics resident noted, "I had no idea his life [the patient] had *quality*. Every time I've seen this patient in the hospital he looks miserable and never interacts with anyone. Here at home, he was smiling, he was laughing; that was an entirely different kid." Any clinician who has had the privilege of being invited into the sacred ground of a pediatric hospice patient's home can appreciate this assessment.

Quality, as a metric used to help guide the decision-making of pediatric palliative care patients and their families, is bound in and to the culture of the individual family. It is also tied into setting; quality of life (QOL) defined by the bed-bound patient residing in the intensive care unit (ICU) might look very different from quality as defined by the newly diagnosed asymptomatic patient. The suggestion then becomes that quality must be a fluid metric that is influenced by values and goals established by the patient and family. However, it is possible that clinicians interacting with families have an entirely different definition of quality and subsequent outcomes. Understanding the need for early palliative care integration is perhaps best demonstrated by the following case example.

Case Study: A Patient's Quality of Life

WS was diagnosed at birth with trisomy 13. She initially presented with a ventricular septal defect, rocker bottom feet, low-set ears, microcephaly, clenched hands, and a high risk for aspiration. She was immediately transferred to the neonatal ICU (NICU) where she spent the first 4 weeks of her life. Palliative care consultation was requested to assist her family with decision-making. WS's mother explained, "This feels like it's all been a bad dream, I just want her to get better." WS's father reported feeling overwhelmed by the medical decisions presented by the specialists involved in his daughter's care. After a series of family meetings, her parents decided to bring WS home with a nasogastric (G) tube and safety medications for potential seizures and to make decisions about ventricular septal defect closure and other surgical interventions at a later date. WS's mother spoke often about the nursery waiting at home for WS, and she reported feeling confident that WS would improve if she could just go home.

WS was discharged home with hospice. Her parents had elected to make every effort to keep WS comfortable and had agreed with adjusting her code status to allow for natural death. During a social work hospice visit, WS's mother reported that neither parent had been sleeping and that they felt as though they were staring at her waiting for her to die. She noted, "We really aren't living, we are just walking around like zombies." Home health was introduced to assist with night nursing hours, and, as WS began to gain weight, her parents reported feeling a renewed sense of hope.

After 2 months of home hospice, WS's mother began to question the direction of WS's goals of care. She felt that with WS improving, the family could now revisit the potential for surgical interventions, and she decided to amend WS's code status. She had become engaged online with a network of mothers who also had children with trisomy 13 and began to feel more empowered in advocating for WS. WS's parents requested a transfer from hospice care to palliative care and were excited by the opportunity to throw WS a "hospice graduation" party.

While being followed by the outpatient palliative care team, WS had a successful ventricular septal defect closure and had a button G-tube placed. WS had regular appointments with a variety of specialists, and, after a year of being followed by the palliative care team, her mother would report, "We are doing good!" and even asked, "We love you guys, but do we still need you?" By age 2, WS had surpassed all expectations for her life expectancy.

Shortly after her third birthday, WS began experiencing seizures and increased hospitalizations. Palliative care was reintroduced, and her mother noted that, "This feels different, this feels like the big one." She reported that WS had become much less interactive and worried that WS was experiencing significant neurological delay following the seizures. After a major ICU stay, WS's parents decided to again take WS home with hospice. She died in her own room surrounded by her family and favorite stuffed animals. The mother told her hospice social worker, "WS never had it easy, but she always did things her own way and was the strongest person I know."

Outcomes Considerations and the Power of Social Networking

The experiences described in WS's case study illustrate the challenges families face when navigating goals of care. In the case of trisomy 13 and 18, many clinicians refer to both diagnoses as "lethal conditions," and many families have reported experiencing bias by clinicians due to their child's diagnostic label.[3] While WS's parents were not aware of her diagnosis until birth, the research suggests that when trisomy 13 and 18 are discovered in utero, families are often counseled toward termination.[4] Remarkably, despite feeling the pressure to terminate, the majority of parents elected to continue their pregnancy. In a survey of parents facing prenatal diagnosis of trisomy 13 and/or 18, parents chose to ignore recommendations toward termination based on their own reported moral beliefs (68%), child-centered reasons (64%), religious beliefs (48%), parent-centered reasons (28%), and practical reasons (6%).[5] This research demonstrates the disconnect that can exist between clinicians and parents when determining treatment courses for their medically fragile children.

The working assumption that trisomy 13 and 18 were lethal congenital anomalies that were not compatible with life was generally validated by what clinicians were seeing in practice.[6] A retrospective cohort study found that among children born with trisomy 13 and 18 in Ontario, Canada, early mortality was the most common outcome; however, 10–13% of children survived for 10 years, and, among children who underwent surgical interventions, 1-year survival was actually high.[7] So how should palliative care clinicians approach assisting families with decision-making in the face of such prognostic ambiguity and potential clinician bias?

The palliative care clinician should not only attune him- or herself to what families might be hearing from their primary medical providers, but also consider what families might be learning in their own examination of the diagnosis. In the example of trisomy 13 and 18, clinicians relied on the multitude of resources that suggested this diagnosis will mean extreme suffering and shortened life span. Meanwhile, families researching the condition on the Internet were introduced to an alternative narrative, one that suggested that patients who do survive experienced meaningful lives and QOL.

Parents, like WS's mother, who engage with parental support groups online may discover an alternative positive description about children with trisomy 13 and 18.[5] A quick Internet search reveals shockingly different results when the words "trisomy 13 and 18" are used alone versus "trisomy 13 and 18 support." While the diagnosis-alone Internet search yields a clinical, medically complex, and seemingly negative perspective, the diagnosis and support search brings one to a multitude of support groups such as the Support Organization for Trisomy (SOFT), which presents smiling children and relatable language. Understanding that families might hold the clinical perspective and the support perspective in equal regard will help the palliative care clinician help families navigate decision-making through uncertain outcomes.

Guiding with Uncertainty

The sometimes dichotomous relationship between the perspective of the clinician and the patient and family is no more evident than when considered through the lens of prognostication in pediatric life-limiting illness. In the case of cancer, which remains one of the leading causes of nonaccidental death in childhood, one study reports that children who die of cancer experience significant suffering and inadequate palliation in the last month of life.[8,9] The team investigating these parent-reported outcomes suggested that unrealistic prognostic expectations, by both physicians and/or parents, may be leading to inappropriate treatment goals. A survey of parents of children who died of cancer between 1990 and 1997, along with 42 pediatric oncologists, confirmed that parents first recognized that the child had no realistic chance for cure a mean of 109 days before the child's death, while physician recognition occurred earlier at 206 days before death,[10] furthering the idea that palliative care often acts as a bridge between medical understanding and family understanding.

Considerable delay exists in parental recognition that children have no realistic chance for cure, but earlier recognition of this prognosis by both physicians and parents is associated with a stronger emphasis on treatment directed at lessening suffering and greater integration of palliative care.

Case Study: A Patient Undergoing Hematopoietic Stem Cell Transplantation

MM was a 17-year-old boy of Indian descent. He lived at home with his parents and younger sister. He was born with a severe primary immunodeficiency which had presented through his life as recurring, long-lasting infections. These infections caused MM to spend the majority of his school-aged years in the ICU for treatment. Despite these challenges, MM maintained high grades in school and even managed to frontload his classes to allow him to graduate a semester early. Under advisement of his medical team, MM and his family decided to pursue hematopoietic stem cell transplant through bone marrow transplant.

Following hospital protocol, the pediatric palliative care team was consulted to meet MM and his family at time of transplant. During the initial consultation, MM described his choice in timing for transplant and explained, "I'd rather take a year off now, finish up my last semester, and go into college without having to worry about this." When asked if there were things he worried about regarding transplant, he remarked, "I mean, I guess I'm worried it won't work, but I don't want to spend the rest of my life in and out of hospitals, so it's worth it." MM's parents were actively involved in his decision-making process and remained hopeful and confident in their decision to proceed with transplantation.

During the engraftment period, MM and his family engaged easily with care team providers. Like many of his peers, he loved discussing sports and technology with all providers who visited him. MM was discharged from the hem/onc unit after 30 days of engraftment. MM reported looking forward to getting home and playing video games and catching up with his friends as he continued the recovery process. A week after discharge, MM returned to the unit with low counts and fever. His family was understandably discouraged by this admission and worried that this was indicative of complications from transplantation. MM had lost almost all of his hair and had severe nausea. This was especially challenging for his family, as his mother identified feeding MM as a primary exhibition of her love and care.

MM would always be the first to tell staff that he loved food, and any restrictions on his eating habits felt like a major setback. MM had grown close to his primary nurses, palliative care social worker, and child life specialist, routinely requesting visits to "check in" and report on new Apple products or projects he was working on. He arranged a special Super Bowl viewing party in his room on the floor and invited all staff and his friends to attend. While MM remained upbeat in his interactions with his teams, his condition worsened.

MM developed graft-versus-host disease, which presented with skin sloughing and progressive gastrointestinal involvement. MM was acutely aware of his decline, and, during one visit with his palliative care social worker, when asked if there were things he was worried about, he tearfully replied, "I'm worried I won't get to do the things I want to do with my life." MM was a very imaginative young man and was able to explore some of these "bucket list" items through guided imagery. All of the teams involved in MM's care had grown close to MM and his family. In a preconference to a care team meeting, each of his specialists had begun speaking about the aspect of MM's disease process that he or she was responsible for when the palliative care physician interjected, "no one is acknowledging the reality here; MM is dying."

While each clinician cognitively understood this clinical reality, the team was challenged with how to communicate this to a family who had been such strong advocates for hoping against hope. When the change in MM's prognosis was presented to his parents, they explained that they needed to maintain hope and that there were forces outside those of medicine that might intervene. They both felt that the care team had become "like family" and reported that MM would want to be on the unit in the event he should die. When asked what they felt brought their son comfort, MM's parents reported that he loved listening to his favorite book read aloud. During the last 3 days of MM's life, he remained unresponsive while members of the care team and MM's parents took turns reading MM's favorite book aloud to him.

Parent Outlook and Understanding

While hematopoietic stem cell transplantation presents the potential for cure for patients like MM, it remains an intensive therapy that presents many risks for complications and lasting health effects.[11] Can families truly understand what the transplantation process could look like? Understanding patient and family perspectives on proposed interventions is essential to facilitating goals of care conversations. In the case of bone marrow transplantation, one qualitative study found that parents reported being either incapable or unwilling to think about the potential for negative outcomes. Some parents refused to acknowledge the possibility that their child might die, in order to move forward with transplantation.[12]

In MM's case, this was certainly true for his parents. He had spent his life dealing with infections that had the potential for significant harm, so a path without transplantation still presented significant risk to MM's life. If they elected not to move forward with transplantation, they could imagine a future decline. However, transplantation presented the possibility of a different future, a future that was *potentially* symptom-free and curative. At one point MM's mother even remarked, "If it doesn't work, he will be sick, and he's always been sick." What they repeatedly reported not "being ready for" was the way things like graft-versus-host would present. They had read that this was possible, but they had not imagined what it would be like to see MM experience significant pain with the slightest touch. They had not imagined seeing MM's skin break down to the point of bleeding, or that he would become too weak to walk the short distance to his bathroom.

Fortunately, palliative care consultation began early for MM, and continued conversations about his parents' outlook and concerns throughout the entire transplantation course were possible. This type of communication can greatly assist parents with coping during this uncertain process.[13] Research centered on parent outlook in hematopoietic stem cell transplantation helps make the case for early and often goals of care conversations. The team concluded that, "understanding parent outlook is a cornerstone of clear and compassionate communication throughout the course of hematopoietic stem cell transplantation, allowing mutual understanding of hopes, fears, expectations, and goals of care."[14] In MM's case, this meant continued readjustment of goals of care as his disease progressed. The trust necessary to hold both hope and prognosis was well established through continued open and honest communication.

Clinician Impact on Bereavement Course

Understanding parent and family perspectives is essential not only for providing care during the illness trajectory, but also in assisting families through their bereavement. Communication and continuity of care are two of the most important aspects of the parent-reported grief experience that the clinician can impact.[15] Many families will want to reconvene their care team to ask, "Did I make the right decision?" or "What could I have done differently?" These meetings can be an important opportunity to revisit family decision-making and reiterate that parents have made the most loving decisions possible with the information they had available.

These bereavement care team meetings can have significant impact for families. Four major meaning-making processes have been identified in qualifying the impact of these meetings. These processes include sense-making, benefit-finding, continuing bonds, and identity reconstruction.[16] See Tables 60.1, 60.2, 60.3 and 60.4 for detailed descriptions of the four processes and examples of parental response. While it remains unknown the extent to which meaning-making during bereavement meetings affects parent health outcomes, the research in the PICU setting suggests that bereaved parents are at a high risk for complicated grief and that meaning-making is associated with a reduction in the severity of these symptoms.[16]

Consideration should also be given to the bereaved sibling. The loss of a sibling can have significant impact on the life course of the surviving sibling. In MM's case, his sister, CM, spent most of her afternoons doing homework in MM's hospital room. If she wanted her parents present for something in her life, MM's illness always had to be considered. Many of the same challenges in meaning-making exist in the bereavement course of a sibling. How a sibling experiences the death of a child could impact his or her long-term psychosocial well-being. Sibling-directed communication and concurrent supportive care during the illness experience and the immediate bereavement course may mitigate poor long-term outcomes.[17]

Communication throughout the Trajectory

When caring for children with complex life-limiting illnesses, communication needs change rapidly and sometimes unexpectedly. Given the uncertainty of prognostication, effective communication surrounding goals of care is essential. Guiding conversations around goals to address physical, emotional, spiritual, and social needs is

Table 60.1 Sense-making processes observed during follow-up meetings ($N = 35$)

Sense-making process	Example (follow-up meeting number)	n (%)[a]
Biomedical explanations	Do you think there's anything we should be asking as far as from a medical perspective that maybe we're just not—any information that we should know that we might not already know? (#21)	34 (97)
Details of illness	What about the high blood sugar? . . . And did his weight have anything to do with it? (#4)	32 (91)
Course of illness	My question was how things happened chronologically. For me it was a blur. (#28)	27 (77)
Counterfactuals	I just have the "what-ifs," like what if we waited one day and they would have done surgery. (#23)	23 (66)
Cause of death	Do you know what her cause of death is? Is it blunt force trauma to her head? (#8)	20 (57)
Autopsy	So was there anything in the autopsy that was surprising or significant? (#25)	13 (37)
Parents' prior decisions	You're always going to have that question whether or not you made the right decision. (#21)	24 (69)
End-of-life care	One of B's main concerns is that we didn't pull the plug too soon or gave up on her too soon. (#23)	17 (49)
Treatment	The feeding tube, we understand we want to try to feed him . . . But was it worth it? (#15)	14 (40)
Blame	What happens is a lot of times when you try to get all the answers' you're trying to find somebody to blame. (#30)	18 (51)
For child's death	You can tell me when my pizza's going to be here. But you can't tell me when they're going to be here to pick up a child who's dying? It's just unacceptable. (#41)	9 (26)
For parents' experience	Why did it take 4 hours for the nurse to call us? If they're telling us everything started around 9 P.M., we didn't we get a call until 1:15 A.M., and we're a half an hour away. (#16)	16 (46)
Blessings	And every day he lived was a blessing. Every day was better than anybody had ever told me. (#29)	18 (51)
Inevitability of death	Even though he had his ups and downs, he was on a downward cycle. (#25)	18 (51)
Parents' role in the death	Has smoking ever been connected to any kind of heart problem in pregnancy? I smoked when I was pregnant. (#32)	15 (43)
Downward comparisons	There's been a couple sudden deaths in our area . . . In some ways that would be even harder. (#13)	14 (40)
God's will	Maybe that was her day to be with the Lord. (#11)	13 (37)
Did everything	I do believe you all did everything you could to save my daughter. (#20)	11 (31)
No longer suffering	He's in a good place, he's not suffering anymore. (#3)	7 (20)
Exceeded expected age	I had 9 months. Nine months that technically I never should have had. (#10)	7 (20)
Child's will	He (child) told Dr. S, "I'm not having no more surgery." He said, "This is my last one." (#22)	4 (11)
Why me?	It's unfair, but it's my life, you know. This is what I was dealt. (#2)	3 (9)
Parent not capable	I know I can't handle a sick baby . . . I wouldn't be able to take care of a sick child forever. (#2)	2 (6)
No sense made	When we got the results back, basically we were told they didn't find anything wrong. So we're still left without an answer. . . . It's like getting handed a blank piece of paper. It's like, why? Why did we go through what we went through for no answer? (#16)	9 (26)
No need to make sense	I believe this stuff happens and that's just how it was supposed to happen, you know. Left your house an hour early, got in a car accident, that's just what was supposed to happen. (#2)	9 (26)

[a] *n* (%) = number and percentage of follow-up meetings demonstrating each meaning-making process.

Table 60.2 Benefit-finding processes observed during follow-up meetings (*N* = 35)

Benefit-finding process	**Example (follow-up meeting number)**	***n* (%)[a]**
Ways to help others	We're trying to get to the point where we can help, instead of them helping us. (#13)	29 (83)
Feedback	It's a lot easier to have repetitive nurses than to keep having new ones take care of your child. . . . To ask the parents if they would rather have that would be nice for other parents. (#3)	15 (43)
Donations	I was lucky that we had this equipment sitting around to donate to them. (#22)	8 (23)
Research	I just didn't want to not participate in the research to help other families. (#21)	8 (23)
Volunteerism	And as far as any sort of parent outreach or anything that you need I would feel—I would always be open and available to helping any way I can. (#33)	5 (14)
New medical knowledge	I know that he was sent here for a reason and, like I said, now these doctors know what they need to do for the next baby. (#10)	6 (17)
Organ donation	It comforts us knowing that she would be able to live on through other people. (#17)	2 (6)
Change in others for the better	Even in his slow motion, he helped them slow down and smell the roses and think better of what they were doing. (#7)	90 (26)
Change in parents for the better	I feel like she helped me get to a different appreciation and respect things on many different levels way different than I did before. (#21)	7 (20)

[a] *n* (%) = number and percentage of follow-up meetings demonstrating each meaning-making process.

necessary to ensure holistic care is delivered. Communication is the basis for all decision-making, and, throughout an illness trajectory, decision-making hinges on effective communication.[18] Providers must understand how to meet a family where they are in order to foster open communication around the issues that are most important to the patient and the family.

When families are faced with having to make hard healthcare decisions for their children, open and effective communication impacts how information is received. The necessary communication skills that the provider must possess include marrying effective general communication with complex medical topics and patient-centered decisions.[19] Training medical professionals how to effectively communicate with their patients builds confidence in the provider. This confidence then facilitates a trusting relationship in which difficult conversations are more productive.[20]

Preparation for the conversation is key for the provider and the family. Understanding the goals of the communication and the topics that will be covered allows the participants to feel more at ease with the expectations. Giving space for the concerns of the family and how they will best be supported in having difficult

Table 60.3 Continuing bond manifestations observed during follow-up meetings (N = 35)

Continuing bond	**Example (Follow-up meeting number)**	***n* (%)[a]**
Parents' inner lives	Every time I hear a bird I think of him. (#9)	33 (94)
Child attributes	She had a strong personality, that one. She had the biggest, biggest brown eyes ever. She was so beautiful. (#4)	28 (80)
Child life events	He played baseball, he played soccer. He'd drive the power chair around the bases on his own, stealing bases and everything. (#1)	21 (60)
Personal rituals	We wanted to take our little girl home with us in our way instead of having her sitting in some cold place. (#31)	21 (60)
Photos	Just have a family picture here of all of us. (#5)	18 (51)
Linking objects	So you know it's still sitting there. His diaper pail is, gross as it is, we haven't emptied it. (#15)	17 (49)
Angel	My friend's grandpa was having surgery for cancer . . . the first thing I did was I looked up and I was like, " [deceased child], can you look out for grandpa?" (#8)	8 (23)
Imagine	I can only imagine what she would have said if she was still living. . . . (#13)	3 (9)
Parents' social world	I just have to talk about her. (#20)	26 (74)
Community	The funeral director said he had never seen so many people come out for a baby. They ran out of flags for the cars; that's how many people came out. (#16)	19 (54)
Health professionals	It really meant a lot to me how good they were with R and how much they treated her like a child and not a series of medical events. (#18)	15 (43)
Siblings	They talk about her a lot, if I say, "C, who's my favorite daughter?" She's like. "Your favorite daughter on earth is me; your favorite daughter in heaven is her." (#5)	7 (20)

[a] *n* (%) = number and percentage of follow-up meetings demonstrating each meaning-making process.

Table 60.4 Identity reconstruction process observed during follow-up meetings (*N* = 35)

Identity reconstruction	Example (Follow-up Meeting number)	*n* (%)[a]
Good parent	I have no doubt that I did a really good job caring for him. (#6)	23 (66)
Life changes	I have to figure out what my purpose is now. (#18)	22 (63)
Relationships	I had another baby. Yeah, L, and everything's well with him. And that's kept me going. (#4)	18 (51)
Work	I am getting ready to go back to school and hopefully going to be up here working soon. (#10)	9 (26)
Environment	She said, "We have to sell the house. . . ." We have another house on the river. We bought it a few years ago for investment . . . So he said, "Fix that up and we're going to go." (#34)	5 (14)
Travel	We're going on a cruise . . . getting away, just the two of us . . . we met on a cruise 22 years ago. (#1)	2 (6)
Hobbies	I'm back to the choir now . . . I got to do something I like and he liked, and so I'll do it in his honor and move on. (#1)	1 (3)
Number of children	There's always that question, how many kids do you have? I hate that question. I have four kids, but . . . (#2)	2 (6)

[a] *n* (%) = number and percentage of follow-up meetings demonstrating each meaning-making process.

conversations is essential to ensuring productivity. This facilitation fosters trust and opens the door to effective communication regardless of how difficult the topic. Conversations that help align family perspectives and values with anticipated medical outcomes will be more accepted if the communication is trusted and facilitated appropriately. This rapport allows for trust during the times when communication is occurring with medical uncertainty and the communication is rapidly changing. "Parents consider communication to be the principal determinant of QOL, regardless of symptom management."[21]

Communication surrounding goals of care across the illness trajectory empowers the patient and family to make informed decisions in the face of uncertainty. An interdisciplinary approach to goals of care communication ensures that all aspects of the patient's care are being addressed. Cohesive goal conversations hinge largely on care providers being consistent in their messaging and collaboration as a healthcare interdisciplinary team. When planning communication, whether there is a need to revisit goals or have an initial meeting, making sure that all disciplines are involved will ensure that the patient's needs are effectively and globally addressed.

Case Study: A Patient with a Congenital Heart Defect and Hydrocephalus

JR was diagnosed at birth with a congenital heart defect and hydrocephalus with shunt placement. He spent 9 months in the NICU/PICU. He was discharged home with private duty nursing services and the durable medical equipment needed to provide his in-home care. His mother was given education and training over a 3-day period, and she had attended roughly six care team meetings throughout his hospitalization.

He was home for a week and returned to the hospital following a code event at home. During his rehospitalization, it was discovered that his shunt had malfunctioned and would have to be replaced. During surgery, he suffered a cardiac arrest and was resuscitated. His shunt was externalized due to infection, and he was admitted from the operating room to the PICU on ventilator support. JR spent another 4 weeks in the PICU prior to a palliative care consult occurring. The palliative care consult occurred following another code event and unsuccessful conversations with the mother regarding his code status and prognosis.

Following the palliative care consult, a care team meeting was scheduled with the mother. The meeting was to include the PICU physician, PICU nurse, neurosurgeon, cardiologist, social worker, palliative care MD and nurse, and the child life specialist for the PICU. The palliative care team nurse met with the mother prior to the care team meeting and discussed JR's trajectory and care goals. The mother stated that, prior to the palliative care consult, she had not understood the severity of the patient's condition even though he had multiple code events and there had been previous conversations about the futility of treatment. She understood from previous meetings that JR would have unique healthcare needs, but she did not understand that the illness trajectory would include making decisions regarding limiting interventions. JR's mother stated that she understood that, due to his fragile state and the recent decline in his health status, changing the focus of his medical treatment would need to be discussed in the upcoming meeting. She expressed that she felt that his QOL during this hospitalization had declined. She reiterated understanding the need for the upcoming care team meeting.

The morning of the care team meeting, the palliative care nurse met with JR's mother once again and reiterated the goal of the meeting and who would be in attendance. JR's mother was given the opportunity to ask preliminary questions of the palliative care nurse so that the care team would be prepared for the meeting as well. During this meeting, JR's mother was engaged and asked appropriate questions. Care goals were discussed, and JR's mother asked for more information on a tailored resuscitation plan for JR instead of signing a do-not-resuscitate (DNR) form. The care team met after the mother left the meeting and agreed that this was the most productive care goal meeting since JR was admitted in the PICU. The palliative care nurse also met with the mother following the meeting to ensure that the message she received during the meeting was consistent with the team's intentions. The overall satisfaction of the team and JR's mom improved following this level of communication.

Communication and Impact on Outcomes

JR's case illustrates how patient outcomes are directly impacted by the way communication is handled. Parental reports of dissatisfaction can stem from the way in which communication was handled during the critical times of their child's illness trajectory. Similar to JR's case, families report that they are not confident in the medical knowledge provided; they feel there is a lack of emotional consideration, a continued emphasis on a cure without realistic conversations surrounding refocusing care goals, a delay in this realistic communication, and a lack of privacy during these delicate conversations.[19]

Even though the intention of the care team was to provide JR's mother with education and guidance regarding his diagnosis and prognosis, the tenuous environment of the PICU challenged JR's mother's communication needs. The rapport necessary to foster the trusting relationship needed for these difficult conversations effectively has to be established early on in the trajectory.[22]

Families express that the information they find most critical during early diagnostic discussions are "symptom management, what to expect from the diagnosis, and what testing is necessary."[19] Parents who report good communication experiences with their healthcare providers include such contributing factors as communication skills that included open and sympathetic dialogue and direct communication regarding the diagnosis in private with adequate time to absorb and clarify the information provided.[19] Parents like JR's mom express the inherent desire to have their needs valued and heard.

Value-Based Decision-Making

Just as parents want their child's needs communicated and valued, they also want to know that the decisions they are making regarding the care of their child are based on the values that are important to them. The child's value and significance is important to the family, and how care goals are handled by providers has a reflection on this value. Engaging conversations around goals of care not only to include what medical needs may be present, but also understanding the importance of the family's values will guide these goals regardless of the medical trajectory. "Quality of life" is defined by the World Health Organization as "an individual's perception of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."[23,24] Promoting an environment where QOL and personal values are at the forefront when discussing goals of care will foster collaboration and cohesiveness.

The hematology-oncology team at San Diego's Rady's Children's Hospital established a Supportive Care Program to ensure that QOL was at the center of the care provided to patients dealing with life-limiting hematological and oncology disorders. This embedded service did not require a consult and rather was considered an extension of the primary team.[25] The service facilitates supportive care rounding with patients and their families to ensure that their QOL is being addressed and decisions are value-based. The team utilizes a decision-making tool to "improve communication, identify goals of care, optimize the patient's quality of life, and formulate a plan of care."[26] An evaluation study was conducted to evaluate family satisfaction with the supportive care team and the effectiveness of the decision-making tool. The study also captured what impacted a family's decision-making.[19] "The child's quality of life, chances of improvement, and level of pain and discomfort were all rated significantly higher in importance than other factors."[26] Participants in the study were also asked which members of the team had a significant impact on the decisions that they made for their child, and every participant listed the nurse as a key component. The use of clear and concise communication throughout the illness trajectory, as illustrated through this study, improves perceived QOL and support throughout the decision-making process.[9]

Preparing Families for Uncertainty

> "If we focus on what we can't do, we will never get anywhere."[23]

Patients and families report realistic expectations about the possibility for decline when faced with life-limiting illnesses, but uncertainty around when or how this decline will occur.[27] The complexity of the illness and making value-based decisions for their child's health management can be complicated by this unknown. "Parents confronted with the fact that their child's health had declined over time talked about *when* the child would die in contrast to parents faced with the immediate threat of acute changes who talked about *whether* the child would die."[21]

Pediatric palliative care is designed to support families through this uncertainty with a collaborative team approach that changes as the patient's and/or family's needs change.[28] Understanding the changing landscape of the illness trajectory is both crucial and difficult for healthcare providers and parents alike. Parents do not expect that healthcare providers have all of the answers, but instead seek honest and caring providers who are available to answer their questions.[22] Uncertainty throughout the illness trajectory is not an unexpected difficulty; however, the challenge comes with preparing families and patients to anticipate changing care goals. Palliative care should be delivered in a way that anticipates these unique and changing needs. This care should be delivered in a flexible and collaborative manner while anticipating the needs of the patient and family.[28]

The timing of palliative care involvement plays an important part in establishing care goals that transcend the initial diagnosis. Integrating the palliative care team as part of the primary care team will foster the trust necessary when uncertainty and difficult conversations present themselves. "Key components of palliative care, for both children and adults, include not only pain and symptom management, but effective patient–provider communication, support for decision-making, coordination of care, spiritual, emotional and psychological care, and bereavement support."[29]

Whether the child has been chronically or acutely ill, changing trajectories and uncertain outcomes are stress-inducing for the parent. Parental fear and anticipation of the next hospitalization or setback is a constant when caring for a child with a life-limiting illness. The decline may have been seen over a longer period of time, or it may be a more rapid illness that prompts the hospitalization that could mean the change in their current trajectory. Provider support for both the physical and emotional needs during this critical time is invaluable. Palliative care has often been considered when having end-of-life conversations, when, in reality, palliative care is most supportive when utilized across the illness trajectory to ensure the anticipation of changes in the patient's goals of care.[30]

Case Study: A Patient with a Changing Trajectory of Care

Payton was diagnosed right after birth with a rare genetic disorder that affected her overall health. She started her life complicated by cataracts, hip dysplasia, a heart murmur, and hearing loss. By her first birthday, she would endure eight surgeries. This would be the beginning of a long, complicated medical course that would be defined by uncertainty. Her mental capacity never developed past a 9-month-old level, and she would never have the ability to sit, crawl, or talk. Her trajectory was complicated by new medical challenges constantly, and, over the span of 6 years, she would endure 20 surgeries and countless hospitalizations. Each hospitalization brought a new set of concerns and goal changes, but what was considered a return to baseline at the conclusion of each hospitalization. Her mother reported, in retrospect, that there had been a very slow and steady decline in her overall baseline that was not overtly apparent to her, given the fact that she was her caregiver every day.

At age 6, Payton was hospitalized with what was thought to be feeding intolerance. During this hospitalization, Payton's parents participated in daily rounding with the medical team. They were briefed on her changing health status and the uncertainty of what might be occurring. They reported that this was not new for Payton. Given the rarity of her case, it was common for there to be uncertainty. The difference with this hospitalization would be the uncertainty in not what was acutely happening with Payton, but whether she would recover from this setback. With no pediatric palliative care team available, the general pediatric team managed her care day to day and consulted specialists who could speak to the many complex health needs Payton and her family were experiencing.

Payton had been hospitalized for 2 weeks when it was apparent that this was not going to be a typical hospitalization. Her lab values could not be normalized, and her body seemed to be "shutting down" according to her mother. On hospital day 17, an outside pediatric hospice team was called in to consult on Payton's case and determine the possibility of providing care at home. Upon meeting with Payton's mother, it was determined that she understood that the likelihood of Payton returning to her baseline health status was not expected. During this meeting, it was discussed that Payton's parents wished to begin focusing on her symptom management and not continuing to put her through the exhaustive testing she had endured while trying to come to a conclusion about her decline. The primary pediatrician caring for her during this hospitalization was also present for the meeting and obtained the documentation of the family's wishes for Payton's care directives. Payton now had an order to allow natural death in place, and, due to the symptom burden of her enteral feeds, they were discontinued.

Her family was given time to absorb the information delivered in the care team meeting, and a follow-up meeting was scheduled for the following day to discuss further care planning. During this follow-up meeting, the pediatrician, hospice nurse, social worker, and child life specialist conferenced with the family to answer questions and discuss where the family would like to be when Payton died. Given the complexity of Payton's care and a sibling living in the home, it was decided that she would remain in the hospital under the care of the hospice team, in collaboration with the hospital care team. The family was provided with memory-making and legacy-building opportunities. A hospice care plan was developed to provide physical, emotional, and spiritual support during this time. On the 40th day of her hospitalization, Payton died with her family present. Her family was provided bereavement support for 2 years following her death.

Payton's mother reflected that "there were so many increasingly complex medical issues at play, and no form of treatment was going to 'fix' her condition. Being connected to the appropriate hospice team members allowed our family to have concurrent support as we dealt with our daughter's life-limiting illness on the medical side. The decision to allow hospice to enter the picture was to endeavor to have a compassionate support team come alongside us as we journeyed through the end of our daughter's life on day 40 of our stay. The compassion and empathy demonstrated to our family during this time truly helped in our transition from illness to loss and grief. Hospice care became an invaluable resource for each of us during this time."

Clinician Challenges when Leading through Uncertainty

As illustrated in Payton's case, uncertainty is a constant when caring for patients with life-limiting illnesses. Supporting families through rapidly changing health status and goals of care is challenging at best. Understanding the delicate balance between hope and realistic expectations is essential to the well-being of the patient, family, and clinician. Clinician support is often overlooked in the pursuit to care for the patient and family. "The severe illness and death of a child is out of the 'natural order' of things. Bearing witness to the isolation or suffering of children is distressing for families and providers alike."[31]

Clinicians need support while guiding families through uncertainty. Without proper support, clinicians can become ineffective in the care they are able to provide, which will further complicate the course. Promoting a professional environment that validates the providers' needs throughout the time they are caring for a complex patient will foster healthy discussion and support.[30] Understanding their own grief is paramount, given how this grief can impact the care the clinician is able to provide. Clinicians may have been providing care for this patient throughout the illness trajectory, and acute changes in the patient's health status or the patient entering into a terminal phase is emotionally distressing.[32]

Families express effective communication as a consistent theme when discussing their satisfaction with the delivery of care to patients living with complex health needs. In order for clinicians to be effective communicators, they must first understand their personal comfort level with having these conversations and supporting families through uncertainty. To avoid their discomfort being misconstrued as insensitivity, the clinician must fully grasp this concept. Self-awareness is crucial.[33] Understanding this emotional intelligence will aid the clinician in identifying the skills necessary to cope with the emotional challenges that caring for this patient population brings. Clinicians are faced with identifying their own emotions surrounding their mortality and grief processes. Continuously providing care to critically ill children, where the focus needs to shift from curative to more palliative care, is emotionally taxing. Having a grasp of how each clinician handles this emotion is essential to ensure quality care for the patient and sustainability for the clinician.[34]

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CHAPTER 61

End-of-Life Decision-Making in Pediatric Oncology

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Key Points

- Decision-making for parents facing the serious illness of a child is, in most cases, extraordinarily difficult, particularly facing end of life.
- Healthcare providers can influence the extent to which patients and parents participate in end-of-life decision-making by communication style and timing of the discussion.
- Children and adolescents may need assistance making decisions based on their cognitive development, and each patient should be assessed as an individual to determine his or her competence and preference for decision involvement.
- Preferences for treatment should be balanced between the child or adolescent patient and the caregiver or surrogate.
- Nurses have a professional responsibility to facilitate informed patient decisions at the end of life.

Introduction

"Your child has cancer." These are words no parent ever expects or wants to hear. After hearing these words, parents are faced with a myriad of decisions, such as where to seek cancer treatment for their child, what therapies to choose, and how to tell their child about the diagnosis. *Treatment decision-making* refers to the choice between two or more treatment options. Families are also faced with decisions about everyday life, such as whether or not to return to work while their child is undergoing cancer treatment, which family members to involve in care, and who to trust for accurate information. While adults with cancer or other serious illnesses typically make their own healthcare decisions, parents must make decisions in the best interest of their child. In this chapter, we refer to "parents" as the biological parents or legal guardians who have decision-making authority for a child. We use the term "child" to refer to all infants, children, adolescents, and young adults unless we are referring to a particular developmental stage of a child.

Parents' treatment decision-making for their child may be impacted by family dynamics, prior decision-making experiences, prior healthcare experiences, and the impact of culture and/or spirituality. Members of the healthcare team must provide accurate and timely information about the child's underlying illness and treatment options. This information, along with the child's and parents' prior experience, guides decision-making. Parents struggle to make the best decisions for their child to minimize decisional regret.[1] Nurses are in a unique position to support the child, parents, and other family members through their relationships forged by providing direct care at the bedside. In this chapter, we provide an overview of decision-making in pediatric oncology, including legal and ethical issues impacting decision-making, styles of decision-making, advance care planning, and advance directives. We will describe guidelines to assist decision-making for the child, parents, and the healthcare team, including the role of the nurse (Box 61.1).

Background

The Centers for Disease Control (CDC) reported 23,215 deaths of children from birth to age 1 year, 9,080 deaths from age 1 to 14 years, 28,291 deaths from ages 15 to 24 years, and 21,925 deaths in young adults 24 to 29 years in the United States (most recent data reported for 2014).[2] Infant mortality represents the largest group (28%), with the leading cause of death being related to congenital anomalies. Accidents remain the leading cause of death in all age groups, with suicide being the leading cause of nonaccidental, non–disease-related deaths for adolescents and young adults aged 15–24 years.[2] Cancer is the leading disease-related cause of death for children, adolescents, and young adults aged 1–24 years of age.[2]

While death in pediatrics is relatively rare compared to in adults, these lives represent the loss of the future in our society.[3] These lives also represent significant impact on families and friends. There is also impact on the workforce through loss of parents and/or other family members to care for the ill child or delay in return to work following the death of a child. The kinds of decisions and how they are made may impact parent grief and bereavement as well. Many parents indicate that feeling that they have been good parents, doing everything possible and having their wishes for their child's care respected, is a priority in making decisions at end of life.[4]

Decision-Making in Pediatric Oncology

After a child's diagnosis, parents are faced with decisions regarding cancer-directed and supportive care treatment options. Because pediatric cancer treatment is commonly guided by clinical trials,

Box 61.1 Definitions of Key Terms

Decision: The final choice between two or more treatment-related options.

Capacity: The ability of a person to make a decision, based on developmental and cognitive factors, including age and cognition which impact the person's ability to (1) receive information about the underlying illness and proposed treatments, (2) understand the relevant information and apply it to his or her own condition or the condition of their ill child, (3) have insight into the condition and consequences of treatment options, (4) be able to communicate the decision and reasoning for choices.[13]

Phase I study: The initial stage of human testing of a drug, in which the maximum tolerated dose is established; in oncology, the subjects are usually patients who have refractory disease.

Allow natural death (AND): A term becoming more widely used to describe death from the natural consequences of a disease or injury that emphasizes ongoing supportive care to promote comfort and optimize quality of life.[49]

Do not resuscitate: A physician's order written in the medical record directing that no cardiopulmonary resuscitation is to be performed in the case of an acute event such as cardiac, respiratory, or neurological decompensation.[49]

Withdrawal of life support: The act of discontinuing life-sustaining medical treatments, such as mechanical ventilation, pharmacological support of blood pressure, dialysis, and vasoactive infusions, that will likely lead to death.

Life-sustaining medical treatment: Interventions that may not control the patient's disease but may prolong the patient's life; these may include not only ventilator support, dialysis, and vasoactive infusions, but also antibiotics, insulin, chemotherapy, and nutrition and hydration provided by tubes and intravenous lines.

Supportive care: Comfort measures that exclude curative efforts but could include aggressive symptom management (such as pain relief and hydration) or symptom prevention (such as limited blood product support) as well as interventions to optimize quality of life (such as integrative therapies and play therapy).[50]

many parents do not perceive a choice during initial treatment decision-making. Often parents' first perceived choices occur when initial therapies fail. At this time, parents report factors such as the impact of the proposed treatments on quality of life (QOL), likelihood of relief of symptom distress and ease of suffering, what the child wants, and trust in their child's medical team as being influential to their treatment decision-making.[4,5] Discussion about what parents and the child with cancer value as most important to them is important for decision-making throughout the trajectory of illness but most critical at end of life. Transparent and honest communication with the parents, the child, and with the healthcare team is essential in assisting families with decision-making at end of life.[6,7] Factors that affect decision-making in pediatrics at end of life are summarized in Table 61.1.

Ethical/Legal Considerations in Decision-Making

Healthcare traditionally respects the rights of persons to make their own decisions regarding their health. This is challenging in pediatrics when the child, by virtue of age or developmental capacity, may not be able to make decisions independently. Parents are tasked with making decisions in the best interest of their child. The American Academy of Pediatrics (AAP),[8,9] the American Medical Association (AMA),[10,11] the Association of Pediatric Hematology/Oncology Nurses (APHON),[12] the Hospice and Palliative Nurses Association (HPNA),[13] the National Academies of Science, Engineering and Medicine (formerly the Institute of Medicine [IOM]),[14] and the Hastings Center[15] endorse shared decision-making in pediatrics. In most cases, parents act as surrogates to represent the best interests of their child. When parents cannot act as surrogate decision-makers due to legal or lack of capacity issues, the courts may appoint another legal decision-maker. For some, religious or cultural factors may impact decision-making. For example, in some Islamic cultures, there is a hierarchy of decision-making where Islamic laws influence who can make final decisions and the context in which decisions are evaluated (i.e., if the proposed decision would jeopardize the sanctity of human life).[16] Informed consent is generally required for most treatments and invasive testing, but legal, religious, cultural, and developmental issues may influence what, how, and to whom information is provided to inform decision-making. Providing information to inform decision-making and issues of consent/assent are related but separate issues.

Decision-Making as a Quality Outcome in Healthcare and in Palliative Care

Stakeholders, including payers and consumers of healthcare, want to know what healthcare programs do for patients and families. This may be challenging in palliative care, where the scope of practice crosses many domains. Stakeholders may place different values on any given domain, yet assistance with decision-making is an essential skill for palliative care practitioners and in pediatric oncology care. The National Consensus Project Clinical Practice Guidelines for Quality Care[17] and the American Society of Pediatric Hematology Oncology[18] state that the comprehensive psychosocial care plan includes assistance with decision-making through assessment of capacity, values, and preferences for treatment. Furthermore, they advocate that the child's views and preferences be documented and seriously considered in decision-making.[17]

Section 3506 of the Affordable Care Act advocates for shared decision-making through consensus-based standards and patient decision-making aids.[19] These evidence-based decision aids are designed to improve patient and family understanding of treatment options to assist them to make informed decisions. In adults, decision-making aids helped to elicit and clarify explicit values, resulting in patients making informed decisions that were congruent with those values, produced less decisional regret due to feeling uninformed, and produced less decisional regret due to unclear personal values, and patients felt more active participation in decision-making. Provider–patient communication was also enhanced.[20]

Decisions for children with cancer occur throughout the illness trajectory. The use of decision-making aids could be useful

Table 61.1 Factors that affect end-of-life discussions in pediatrics

Healthcare provider factors
1. Lack of confidence in discussing prognosis and end-of-life issues with patient and family
2. Lack of confidence to face the patient and family after difficult conversations.
3. Lack of comfort in having the conversation at all
4. Lack of experience
5. Lack of knowledge of how to address the patient and/or family's reaction to the information discussed
6. Their own discomfort with death and dying
7. Uncertain prognosis
8. Not knowing or understanding patient and family preferences for receiving prognostic information
9. Lack of understanding of the child's voice in decision-making
10. Lack of knowledge on how much specific information to provide
11. Not knowing when is the right time in the trajectory of the disease to discuss prognostic and end-of-life care information
12. Children may not show serious physical manifestations of disease until near end of life, unlike many adult cancer patients.
Patient factors
13. The child's developmental understanding of their illness and proposed treatments
14. The child's willingness to have the discussion
15. Lack of understanding of the possibility of death due to disease
16. The child may wish to protect their parents by ignoring the need to have the conversation
Parent factors
17. Lack of willingness to include the child in decision-making conversations
18. Lack of parent capacity or confidence to have the discussion with the child
19. Lack of acknowledgement or understanding that the child's illness is a terminal condition
20. Unrealistic expectations for cure
Institutional and/or cultural factors
21. Unspoken standards of care that may limit the child's voice in decision-making
22. Lack of support systems for staff to deal with potential moral distress derived from these difficult conversations
23. Cultural and spiritual/religious norms within the institution and/or community

in guiding parents throughout their child's life to acknowledge that a decision must be made, identify the key stakeholders, and create equity in the decision-making process. Decisions can be presented without bias, investigating the values and preferences of all persons involved in the decision-making process.[9] An important example of decision-making aids being used in clinical care include a variety of tools for advance care planning, which is discussed later in this chapter. Regardless of the approach to decision-making, the individual and family styles of decision-making should be considered in how to present information.

Styles of Decision-Making

Decision-making styles range from being autonomous to following recommendations of the medical team and are influenced by individual child and family preferences, religious and/or spiritual beliefs, and culture (including those of the healthcare team themselves). Regardless of how a child and/or family makes decisions, they must be provided with accurate and timely information regarding the diagnosis, diagnostic testing results, treatment options, risks, and benefits of all potential options, including adverse events and alternatives to treatment, including the option for no treatment.

Autonomous Decision-Making

Some parents prefer to make independent decisions regarding their child's treatment. An older adolescent or young adult may also prefer autonomous decision-making, but in the United States this is only legal for those 18 years of age and older who also have the developmental capacity to make these decisions. While autonomous decision-making respects the ethical principle of autonomy, it does not negate the healthcare team's responsibility to provide timely and accurate information. In autonomous decision-making, the child and family are provided with all information to inform their decision, after which they thoughtfully consider this information and inform their healthcare team of the decision they have made. The healthcare team then acts upon this decision to embark upon the course of treatment.

Can any complex healthcare decision be truly autonomous? Members of the healthcare team have potential biases that can influence what and how information is presented. Unconscious biases can influence which clinical trial is presented or how the clinician's preference for a specific choice is conveyed through verbal or nonverbal communication. For example, phase I clinical trials, which are designed to establish safe dosing and toxicity profiles and not treatment efficacy can be presented to families with either a primary emphasis on the potential for the trial to help the child and secondary emphasis on the purpose of these types of treatment trials, or with a primary emphasis on the specific aims of a phase I trial and secondary emphasis on a small chance that the trial might help the child. Researchers have demonstrated that parents of children and adolescents and young adults (AYAs) who are enrolled in clinical trials cannot always state the correct purpose of the trial.[21] Research is needed to help clinicians communicate effectively in these difficult situations to meet family needs for clear and accurate information and needed emotional support during such decision-making discussions.

Shared Decision-Making

Collaborative or shared decision-making (SDM) honors the expertise of both the healthcare team in understanding the underlying illness and potential usefulness of treatment options; the expertise of the child, as developmentally appropriate; and parents in making decisions in the best interest of their child. This occurs along a continuum (Figure 61.1) where the family considers the expertise and information provided by the healthcare team in light of their own values and preferences. The AAP has long endorsed the involvement of the child and family in the informed consent process; however, discussions continue on how best to engage them in the process.[8]

A recent systematic review of pediatric decision-making intervention trials showed that SDM interventions improved knowledge

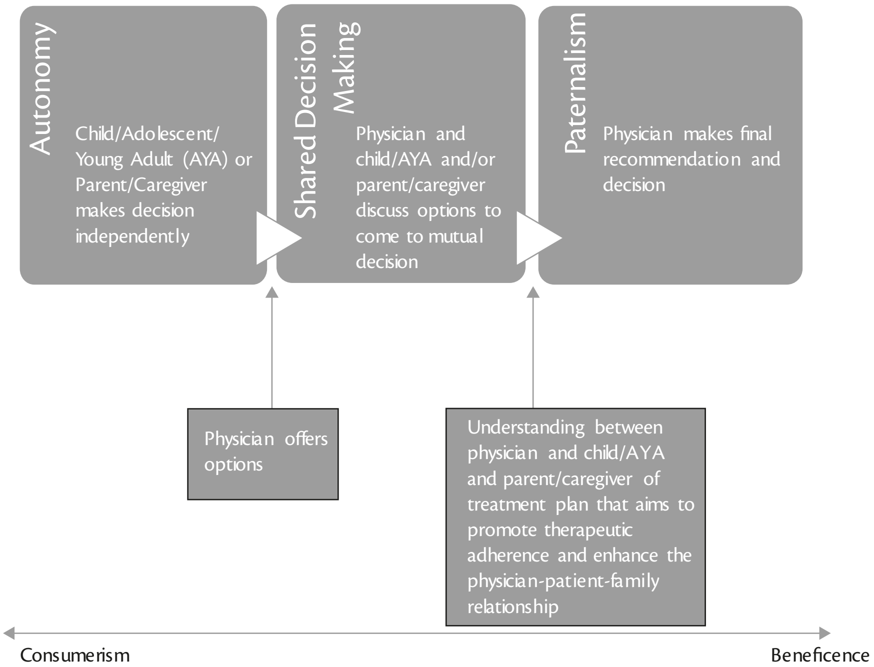
Autonomy
Child/Adolescent/ Young Adult (AYA) or Parent/Caregiver makes decision independently
Shared Decision Making
Physician and child/AYA and/or parent/caregiver discuss options to come to mutual decision
Paternalism
Physician makes final recommendation and decision
Physician offers options
Understanding between physician and child/AYA and parent/caregiver of treatment plan that aims to promote therapeutic adherence and enhance the physician-patient-family relationship
Consumerism
Beneficence

Figure 61.1 Continuum of decision-making.

and decreased decisional regret but did not improve satisfaction with the decision-making process.[22] The use of randomized clinical trials in SDM research in pediatrics is rare. Most studies are small quality improvement or pilot projects. Researchers primarily targeted parents in SDM research; children were rarely studied. When asked in a developmentally sensitive manner, children can articulate their feelings and what is most important to them. This information can be incredibly valuable to guide parents and the healthcare team in decision-making and about what interventions to offer.[22,23]

Defining the role of the parent relative to the role of the child is not well understood because most studies of pediatric SDM targeted parents and not the child.[22] Results from a synthesis of pediatric oncology end-of-life (EOL) decision-making qualitative research showed that parents desire clear and honest communication, delivered with compassion that honors their values and preferences.[4] Continuing to provide hope, focusing on optimizing QOL, and reinforcement by the healthcare team that parents are making good and thoughtful decisions promotes a trusted relationship.

Many parents wanted more time to spend with their ill child, which prompted their decisions to use palliative disease-directed treatments to extend the life of their child; however, in one retrospective study 70% of parents would have decided to forgo life-sustaining therapies, including resuscitation, as the child neared end of life and 20% of parents would have terminated aggressive medical interventions.[4] It is therefore incumbent upon providers to give accurate information about the likelihood for disease control of all therapies and information about anticipated side effects. The healthcare team can assist parents by discussing options for symptom-directed treatments to optimize comfort and QOL at the same time that disease-directed therapies are being introduced. They can emphasize that the option to redirect care from a focus on the disease to a focus on comfort and QOL is available to the family at any time if it is in the child's best interest.

In their systematic review of studies from 2000 to 2016, Sisk et al.[6] noted that parents also need to understand the diagnosis and prognosis. At diagnosis, approximately 66% of parents believed that their child would survive, and, in another study, 50% of mothers and 58% of fathers believed their child would be cured.[4] Parents were more optimistic than their child's physician that the child would be cured.[4,6] Communication of prognosis is essential to parents' understanding and will allow them to make decisions regarding their child's treatment that best align with their values and preferences. What is essential to facilitate effective SDM with parents is accurate and honest communication between the healthcare team and the family (Table 61.2).

Recommendation from the Medical Team

Sometimes parents either ask specifically for or intimate that they need a recommendation about treatment. Whitney and colleagues describe a model of SDM that outlines the conditions under which the physician should make a treatment recommendation (e.g., good prognosis, effective treatment known, as in low-stage Wilms tumor) as compared to times when SDM including the child or adolescent is more necessary (e.g., poor prognosis, no clear best option with lower likelihood of cure, as in relapsed acute lymphoblastic leukemia [ALL] in an adolescent).[24] When a parent asks "what would you do if this was your child?" they earnestly desire an answer.[25] Desiring a recommendation from the healthcare team may be influenced by several factors, such as language barriers, where a family does not clearly understand the information provided, or when the healthcare team has evidence to support that a specific treatment is most likely to obtain cure where others may be sufficiently suboptimal as to cause harm. In addition, this style of decision-making may be utilized when

Table 61.2 Six essential core functions of clinician–patient/parent communication defined for pediatrics[6]

Core function	Definition	Examples
Foster healing relationships	Providing emotional supports and anticipatory guidance to inform understanding of the child's underlying illness and treatment options.	The primary oncologist relays information from the time of diagnosis in an honest, clear, and compassionate way which facilitates trust throughout the trajectory of the child's illness.
Exchanging information	The child, parents, and healthcare team share information about their understanding of the diagnosis, treatment options, prognosis, and anticipated adverse events.	At relapse, the parents provide the primary oncologist with information they have found on the Internet about a promising phase I clinical trial and seek the healthcare team's guidance on enrolling their child in this clinical trial. The healthcare team provides information about any results in previous studies, risks and benefits of this clinical trial, and the child's prognosis.
Responding to emotions	From the time of diagnosis throughout the trajectory of the child's illness, parents and the child may experience a variety of emotions, from anger, denial, sadness, worry, anxiety, depression, etc. The healthcare team acknowledges these emotions and actively seeks to provide appropriate resources to support the child and parents, clarifying their emotional state, communicating understanding, and responding in an empathetic manner.	The mother of a child with a high-risk malignant brain tumor is noted to be crying in the MRI waiting room, while her child is undergoing the scan. The social worker acknowledges that she can see that the mother is upset and asks her to explain why she is in distress. The social worker listens actively to the mother's expressed worries and fears that her child's tumor has progressed because she has seen physical signs and symptoms that are similar to those seen at diagnosis. The social worker validates that she understands why the mother may be worried and reassures her that she will stay with her until the scan is completed, then let the primary oncologist know her worries so he or she can communicate the results of the scan as soon as possible.
Managing uncertainty	There are many periods of uncertainty during the trajectory of childhood cancer. For example, prognosis, unanticipated adverse events, survivorship, late effects of treatment, options for treatment, etc. In managing uncertainty, the healthcare team provides as much information as known to anticipate periods of uncertainty and dispel uncertainty when answers are known.	A child with a relapsed, refractory solid tumor is entering the active dying phase. The family asks when to anticipate death. The advanced practice nurse provides anticipatory guidance of the signs and symptoms of the dying process and how the family can comfort their dying child during this time.
Making decisions	Accurate and timely information on the diagnosis, prognosis, treatment options, anticipated side effects, and alternatives to treatment are essential to making decisions. Communication of this information must be clear, honest, and given in a developmentally appropriate way. The family's values, preferences, and style of decision-making must be assessed carefully.	The physician, nurse, and social worker meet with the family of a patient with a newly diagnosed brainstem glioma. The team assesses the family's understanding of the diagnosis and their values, preferences, and fears. Options for enrollment on a clinical trial, radiation therapy, and palliative care are discussed with the family. The physician discusses the risks/benefits, anticipated side effects, and required testing with the family.
Enabling patient and family health-seeking behaviors	The healthcare team carefully assesses the family's past history with medical care and decision-making, the child's current medical condition with anticipated treatments, and other variables which may affect the child and family's ability to cope effectively. By acknowledging the role of the child, the family, and the healthcare team, better health-seeking behaviors can lead to improved coping skills throughout treatment and beyond into survivorship or a peaceful death, if that is the ultimate outcome.	The social worker performs a thorough psychosocial assessment of the child and family to identify strengths and areas for needed supports. These are communicated to the healthcare team so that a comprehensive plan of care can be developed to address physical, emotional, spiritual, and environmental needs.

cultural or spiritual/religious practices dictate a certain approach to decision-making.

Influences on Decision-Making

Decision-making is impacted by various factors, with communication being one of the most important. Parents who were not offered treatment options report more decisional conflict than those who were offered options. Parents who have choices between treatment options are more likely to feel sure about the decision, understand the information, be clear about the risks and benefits, and have sufficient support and advice to make a choice.[1] Providers should exert extra caution to provide accurate, honest, timely, and compassionate information regarding diagnosis, prognosis, and treatment options, including likelihood of disease control and anticipated side effects. Ample opportunities should be given for the child and family to ask questions and consider options whenever possible. Decisions that must be made in a short time frame or in moments of crisis may be more likely to lead to decisional regret. Providing opportunities for parents to process these decisions might be helpful. It is essential to help parents know that they and the team made the best decisions they could given the child's critical condition and available information.[1]

Yosida et al.[7] identified 23 barriers to end-of-life discussions with children with cancer and their families (Table 61.1). The age of the child and developmental capacity influence the legal obligation to be involved in decision-making.[8,9] Previous experience with healthcare may also impact children's TDM preferences. Children who have had medicalized lives, with frequent hospitalizations, medical tests, and treatments may prefer to be more or less involved in decision-making based on their own values, preferences, and experiences. Most children 8 years of age and older and many children 5–7 years are able to contribute to decision-making by reporting their symptoms and experiences during treatments and their views of QOL to inform decision-making.[23] Children may choose to be actively involved in decision-making or designate a trusted surrogate to make decisions in their best interests based on these experiences. Healthcare providers must consider the preferences of the child to be or not to be involved in decision-making, as informed by the ethical principle of autonomy.

Parents may be influenced by their own previous experiences in healthcare or those of other family members. Parents are more likely to opt for chemotherapy (42/77, 54.5%) compared with healthcare professionals (20/128, 15.6%; $p < 0.0001$).[26] Healthcare professionals present options related to the likelihood of disease control, usually in terms of percentages. Parents then interpret any possibility of disease control as positively influencing a choice of disease-directed therapies. Even in the context of a very small chance of disease control, if only for a limited amount of time, parents may view palliative chemotherapy as worthwhile. Research is needed to better understand how best to present treatment options to parents and children that result in decisions that are consistent with the family's values and preferences and that are not regretted.

Healthcare providers also come with their own values, preferences, experiences, and unconscious biases in relation to decision-making. Physicians are ethically responsible for providing accurate and timely information to the child, as developmentally appropriate, and to parents to aid in decision-making. Some clinicians report that prognostic information can take away hope or cause increased emotional distress for patients and/or families, resulting in conscious or unconscious biases regarding the effect of prognostic information on families from different racial, ethnic, and/or religious backgrounds.[27] Providers must be mindful that parent preferences about how and how much information to receive regarding diagnosis and prognosis is variable, not only between differing backgrounds, but between any given individual within any particular culture, race, ethnicity, or religion.[28] This is further complicated by the fact that accurate prognostication is difficult for even the very experienced clinician. Conversations can therefore be vague, leading to ambiguity for families in weighing treatment options. In some cases, parents may not be offered all treatment options due to the unconscious biases of clinicians. Clinicians may feel certain therapies have little chance of disease control, and, rather than specifically offering their opinion, they do not offer the option to the family at all.[1] At the other end of the ethical debate is whether physicians should offer options they do not feel have a reasonable chance of helping the child.

Pediatric End-of-Life Decisions

The types of end-of-life decisions that families face will vary depending on the underlying medical condition. For the preborn, parents may be faced with decisions about elective termination of pregnancy and/or preferences for birth plans that include end-of-life care when the underlying condition is not compatible with life for longer than hours to days. Parents whose child has a genetic, metabolic, neurologic, or other congenital condition which is likely to contribute to death in childhood or young adulthood may be faced with multiple decisions throughout the child's life regarding invasive supports, such as tracheostomy, ventilatory supports, and/or aggressive surgical interventions depending on the child's condition. Considerations of perceived QOL and the degree to which the child can give and receive joy in his or her life often factor heavily in decision-making in these cases.[29]

Decision-Making in Pediatric Oncology

Most children diagnosed with cancer have normal lives with relatively few medical issues until the time of diagnosis. Parents are faced with multiple decisions about their child's medical care as soon as symptoms manifest; for example, when and where to take their child for medical care. Parents are asked to give consent for diagnostic testing, such as bone marrow aspirate/biopsy, lumbar puncture, magnetic resonance imaging (MRI) scans, other radiology studies, surgical biopsy, and others depending on the suspected diagnosis. Once the diagnosis is made, parents are presented with complicated treatment options such as phase III randomized clinical trials, which in turn contain multiple treatment arms and other decision points. This all occurs at a time when parents are struggling to cope with and understand the diagnosis itself and the impact for the child and family. When there are no clear evidence-based treatment options for cancers with very poor prognoses phase II or phase I clinical trials may be the only options (Box 61.2).

Relapse or Refractory Cancer Decisions

At relapse or when initial treatments fail to achieve the desired results, the child and family are faced with increasingly difficult decisions. Parents must balance their understanding of the underlying condition; information regarding treatment options; cultural, spiritual/religious perspectives; and their innate sense of knowledge of their child with hoping for a cure and at the same time knowing that their child now has a terminal illness. Options are often limited to phase II or phase I clinical trials when available or tailored treatment plans deemed to be best options by the treating oncologist. Some view the recommendation of bone marrow transplant, which is considered as curative-intent treatment for relapsed or refractory cancers, as a "phase II" approach given cure rates between 25% and 50% depending on the type of cancer being treated.[30]

There is a continuum of knowing where the hope for cure transitions to planning for the end of their child's life. For some, this

Box 61.2 Clinical Trials in Pediatric Cancer Treatment

Clinical trials are the gold standard in pediatric cancer care. Most children newly diagnosed with cancer will be treated on a phase III trial where the best-known standard therapy is compared against promising alternative therapies. Efficacy against the specific type of cancer, as well as anticipated side effects, is generally well known. The clinical trial is evaluating two or more treatment options thought to have a reasonably good chance at long-term disease control. Phase II clinical trials test drugs that have been evaluated in phase I clinical trials to evaluate toxicity profiles, but now are being evaluated for efficacy in certain cancer populations. Phase I clinical trials evaluate new drugs to determine dosages and toxicity and to determine the maximum tolerated dose in a variety of types of cancers.[51]

fulcrum of decision-making moves from cure to comfort sooner, while other parents opt to continue disease-directed therapies until the child is actively dying. The healthcare team plays a pivotal role in providing anticipatory guidance so that this change is as gentle and seamless as possible, and the family feels supported in their decisions, thus minimizing crises. Physicians rank the child's QOL as the priority in guiding decisions, where families most often identify hope being of utmost importance.[26]

Parents and/or the child may view this transition as "giving up" or abandoning hope. It is therefore important to support the child and family to maintain hope, yet redirect that hope from cure to optimizing QOL for whatever time the child has left to live. Understanding that parents want to ensure that their child feels loved is important for the healthcare team to align goals of care and recommendations for treatment options. Options for care, including palliative chemotherapy, palliative care, and hospice care should be presented with an understanding of the unique attributes of each specific family. Respecting choices in light of what matters most may also lessen moral distress for healthcare providers as they move from curative intent recommendations to palliative recommendations for care.

Being a Good Parent to My Seriously Ill Child

Hinds and colleagues identified important reasons that influence parent EOL treatment decision-making. In interviews with more than 100 parents of children with incurable cancers across several studies, the majority of parents (approximately 80% within each study) identified their definition of being a good parent as influencing their EOL decision-making on behalf of their very ill child.[31,32] Key characteristics of their definition of being a good parent to a seriously ill child are listed in Box 61.3.[33] These characteristics did not differ by type of EOL decision made or by diagnosis.[35] Parents also identified clinician behaviors that helped them to achieve their definition of being a good parent before their child died.

This research has been replicated in the pediatric intensive care unit (PICU), documenting the most common factor in being a good parent to their seriously ill child including "focusing on their child's QOL, advocating for their child with the medical team, and putting their child's needs above their own."[35] Engaging parents in a discussion of what it uniquely means to them to be a good parent to their child may illuminate the things that matter most to the child and family.[36]

Box 61.3 Parent Themes from Their Definition of Being a Good Parent to Their Seriously Ill Child

Parent themes	Clinician strategies
Doing right by my child	All that can be done is being done
Being there for my child	Staff respect me and my decisions
Conveying love to my child	Staff continue to comfort my child and me
Being a good life example	Staff know our special needs
Being an advocate for my child	Staff like our child
Letting the Lord lead	Staff are pleasant
Not allowing suffering	Staff coordinate care
Making my child healthy	Staff ask about our faith
	Give us the facts
	Staff tell us we are good parents
	Do not quit on us

Decisions for Hospice and Location of Death

Trusted healthcare team members should begin discussions early about what may be expected if the cancer does not respond favorably to treatment so that the child and family have time to consider options and ease transition to hospice and palliative care.[5] Often a family identifies one or two healthcare team members whom they view as most important in their child's care and with whom they will be most comfortable having these treatment discussions. Members of the healthcare team should also frequently discuss the course of a child's cancer experience, including the family's responses, to help recognize when goals of care are shifting. EOL decision-making should include discussion of care issues outlined in Box 61.4.

Box 61.4 Key Considerations in End-of-Life Decision-Making Discussions

Pain and Symptom Management

- What symptoms are most concerning to the child and parents?
- Anticipated symptoms that may occur as disease progresses
- Strategies for pain and symptom management (pharmacologic and nonpharmacologic) with identified processes for problem-solving when a strategy does not produce relief of symptom distress
- Use of opioids in children, with careful assessment of child and parents' fears, worries, and concerns about use of these medications and likelihood of need to titrate dose for pain control in the face of developing tolerance
- Options for palliative sedation in cases of extreme, unrelieved symptom distress, including that the child will likely remain sedated through end-of-life
- Consultation with palliative care specialists, if not already involved, to assist in pain and symptom management

Child and Parent Perspectives

- Manifestations of anticipatory grief and loss
- Managing daily life with some degree of normality
- The importance of parental and family presence
- Experiencing joy in the midst of sadness as acceptable
- Maintaining and fostering communication
- Maintaining connection with the primary oncology team
- Receiving clear, consistent, and honest information about preparing for end-of-life
- Parents preference for early end-of-life discussions with anticipatory guidance provided
- Communicating prognosis

(*continued*)

Box 61.4 Continued

Patterns of Care

- Discussion of preferred location of death (i.e., hospital, oncology unit, ICU, home, inpatient hospice, other settings)
- Discussions of nonbeneficial life-sustaining supports including recommendations for initiation or no initiation of CPR, intubation, noninvasive ventilatory support (BiPAP/CPAP), use of vasoactive medications, use of medically administered fluids and hydration including total parental nutrition, use of antibiotics, diagnostic testing, and other supports that may be anticipated
- Availability and acceptance of home hospice supports
- Completion of state Medical Order for Life-Sustaining Treatments (MOLST), Physician Order for Life-Sustaining Treatment (POLST), Durable Do Not Resuscitate Order (DNR) or other appropriate out-of-hospital form indicating resuscitation status decisions[5]

Decision-making for parents at the end of their child's life relates to perceived or actual suffering. Suffering can take many forms, physical, psychosocial/emotional, spiritual, and environmental. Action and assurances to mitigate suffering impact the QOL of the child and family.[5,33] Agreement on goals of care is paramount to address divergent perceptions of suffering from the parent and healthcare provider perspectives.[5] The child and/or family make decisions based on understanding the information they have received, their wish to help others, trust in their healthcare providers, and individual preferences in care. Outcomes of decision-making about end-of-life care are influenced by parent's perception of being a good parent to their child, perception of QOL for their ill child, and presence and engagement of the healthcare team. Parents who experienced these in a positive way reported less depression and less complicated grief and bereavement.[1] In most cases, parents and healthcare providers prefer home as the location of death for children with cancer.[37] With careful attention to symptom management, child and parent preferences, adequate discussion of EOL care choices, and effective anticipatory guidance, most children with cancer can be well cared for at home. This does not mean that every family will choose home as the preferred location for their child's death. Kassam et al.[37] noted that 30% of parents do not want their child to die at home, but may prefer in-hospital care with specialty palliative care services. Advance care planning will assist with anticipatory guidance and appropriate planning for EOL care (Table 61.2).

Advance Care Planning

Advance care planning is a discussion of values and preferences in care to inform EOL decision-making. It should be distinguished from an *advance directive,* which is a legal document for patients 18 years of age and older that typically names a surrogate decision-maker if the patient is unable to make informed decisions themselves, with preferences for cardiopulmonary resuscitation (CPR) and life-sustaining supports.[13] Advance care planning should be a series of conversations regarding care preferences, often revisited over time as the clinical condition changes, and may or may not result in completion of a written advance directive.

AYAs have unique experiences, unlike those of children or adults. They are experiencing life transitions, such as moving into high school or college or beginning their first postsecondary education job at the same time that they are dealing with serious illness. In a large retrospective cohort study of 663 AYAs who had died from progressive or refractory cancers, it was found that two-thirds of these AYAs had intensive treatments, such as emergency room visits, chemotherapy, or admission to intensive care units within the last 14 days of life.[38] High rates of aggressive medical interventions may reflect poor communication with AYAs about their values and preferences.

Healthcare providers are often uncomfortable with facilitating advance care planning conversations, and parents struggle with initiating these conversations with AYAs. Lyon et al.[39,40] have consistently demonstrated that facilitated conversations by specially trained personnel do not cause undue harm and are desired by parents and AYAs. This facilitator can be the physician or another trusted member of the healthcare team, but trained facilitators who are not part of the AYA's care team may have less unconscious biases which could influence the discussion.[41] Parents and AYAs should be asked for their preferences regarding who is best to facilitate advance care planning discussions for them. Nurses may be in a unique position to provide anticipatory guidance throughout the process of advance care planning (Table 61.3).[13]

Table 61.3 Nurses' role in advance care planning

Clinical practice
◆ Advance care planning is essential to family-centered, person-centered care. ◆ Children and their families have the same rights as adults to honor their values and preferences in care. ◆ Nurses should advocate for the child's and family's voices to be heard, valued, respected, and included in care. ◆ Nurses should honor the child's and/or family's decision not to engage in advance care planning.
Education
◆ Nurses should be educated on the tenets and processes of advance care planning for children with serious illness and their families at any stage of illness. ◆ Nurses should be provided with opportunities for training in the skills to facilitate advance care planning discussions with children and their families. ◆ Nurses must respect and attend to preferences for advance care planning discussions related to culture, ethnicity, spirituality/religion, and other factors unique to each individual child and family.
Institutional policies
◆ Institutions must incorporate advance care planning as a key initiative in quality care for all children with serious illness. ◆ Policies and standards for implementing advance care planning as a standard of care should be developed for all adolescents and young adults 18 years of age and older, and should be thoughtfully considered for younger children with capacity, as well as for certain high-risk medical conditions or procedures with high risks of morbidity and/or mortality (i.e., bone marrow transplant, heart failure, etc.).

Source: From Reference 13.

Involvement of the Child or Adolescent in End-of-Life Decision-Making

Children as young as 7 years can articulate their preferences for treatment, as well as EOL care.[8,10,23] The child's voice is important to decision-making, however, not every child will want to participate in these discussions. The purpose of having this discussion with the child should be reviewed with the parent prior to having the conversation, unless the child is of legal age to make independent decisions.[43] If a child declines to participate in advance care planning discussions, then those wishes should be respected. It is usually very helpful to ask a child who he or she would like to make decisions for them. In most cases, this is a parent, but it may not always be.

There are a variety of tools to facilitate conversations with children. No one tool or one approach will be best for all children. Some examples of advance care planning tools for children are listed in Table 61.4. Capacity to have this conversation should be assessed at the time of the discussion and what exactly is to be discussed. For example, a child may have capacity to name a surrogate decision-maker, but may not have the mature insight to have discussions about choices for life-sustaining supports. Another factor to consider is who should facilitate the advance care planning discussion with a child. It may be the parent(s) or a trusted member of the healthcare team or a trained facilitator. Care should be taken to assess who has a trusted relationship and is best able to ascertain the child's values and preferences. In some situations, the child may prefer a teacher, child life specialist, social worker, chaplain, or another psychosocial team member. In other situations, this may be a physician, advanced practice nurse, or registered nurse. There is no prescriptive way to conduct advance care planning with a child. What works best for one child and family may not be the best for another. Regardless of when, who, and how the advance care planning conversation is implemented, the child's preferences, values, and choices should be respected and honored. Care must be taken to provide adequate time for discussion and reflection of choices and to avoid any possibilities of perceived coercion by a parent, members of the healthcare team, or others. Information obtained from advance care planning discussions should be appropriately documented and communicated to all medical teams caring for the

Table 61.4 Sample tools for advance care planning in pediatrics

Name	Information
My Wishes	https://agingwithdignity.org/shop/product-details/pediatric-my-wishes
Voicing My Choices	https://agingwithdignity.org/shop/product-details/voicing-my-choices
Five Wishes	https://www.agingwithdignity.org/shop/product-details/five-wishes
Shop Talk	https://ccr.cancer.gov/Pediatric-Oncology-Branch/psychosocial/education
Hear My Voice	http://www.albertahealthservices.ca/assets/info/acp/if-hp-acp-gcd-hear-my-voice-ordering-information.pdf
Go Wish	http://www.gowish.org/

Box 61.5 Guidelines for the Healthcare Team to Use in Assisting Pediatric Patients with End-of-Life Decision-Making

1. Seek input of parents as to the timing and extent of information that should be offered to the patient about diagnosis, treatment options, and the likely response to treatment.
2. At the time of diagnosis and throughout treatment, actively seek opportunities to provide information to the child or adolescent that is appropriate to his or her developmental stage.
    a. For a child, ensure parental presence during such discussions.
    b. For an adolescent, ensure a discussion that includes the parents, but offer to discuss with the patient alone as well.
3. Be available to discuss and rediscuss decisions and related concerns in a manner appropriate to the developmental stage of the patient.
4. With parental agreement, encourage the patient to interact with other pediatric oncology patients.
5. Convey verbally and nonverbally the recognition that the patient is trying his or her best and that the healthcare team is committed to the patient's well-being before, during, and after decision-making regardless of decision made.
6. Provide assurances that everything that can be done to help the patient is being done and being done well.
7. As a patient's disease progresses, provide clear verbal (and written, if desired by the patient) explanations of the patient's status. Consider visual explanations, such as showing MRI scans, if developmentally appropriate.
8. With parental agreement, inform the patient of treatment options as they become available in the treating institution or elsewhere.
9. Assess patient suffering and the need to change interventions to relieve such suffering.
10. When end-of-life options should be discussed with the patient, consult parents about the appropriate depth and timing of such discussions.
11. After receiving input from the parents and exploring the patient's readiness for information, discuss the end-of-life options, with
    a. A strong emphasis on the team's commitment to the patient's comfort and to providing expert care at all times.
    b. Professional recommendations.

(*continued*)

Box 61.5 Continued

   c. Descriptions about how the patient is likely to respond to each option (physical appearance, ability to communicate, etc.).
   d. Information about other support resources such as chaplains and ethicists.
12. Include more than one healthcare team member in end-of-life discussions with the patient.
13. Ask the patient what he or she is hoping for now.
14. Allow the patient private time to consider the options with his or her parents.
15. Reassess the appropriateness of the chosen end-of-life options on an ongoing basis, remaining aware that patients will
    a. Vacillate between certainty and uncertainty about the decision.
    b. Need clarification and additional information to resolve uncertainties.
16. Convey respect for the patient's right to change decisions when such changes are clinically feasible.
17. When appropriate to the patient's comprehension level, explain to the patient the availability and value of an ethics and/or palliative care consult for the patient.
18. Maintain sensitivity to any specific ethnic, cultural, or religious preferences during the terminal stage.
19. Demonstrate continued commitment to providing symptom management, support of quality of life, and assurance of the parents' well-being.

child. Permission should be obtained to share this information, not only with the medical teams, but also with the child's parents and/or named surrogate decision-makers in a compassionate manner that respects and honors the child's voice (Box 61.5).

Involvement of the Parent in Decision-Making

Parents usually have the ethical and legal responsibility to make decisions in the best interest of their child. If a parent is unwilling or unable to make decisions regarding their seriously ill child, then careful assessment should be done to evaluate if adequate and appropriate information was provided in a language or format the parents can understand, if the parent understands this information, and if they desire more information or other opinions about options for care, and to discover if any other underlying factors exist that may be influencing decision-making.

In the same manner as for the child, there is not one prescriptive way to have a conversation with a parent regarding advance care planning for their seriously ill child. The same tools that are used for conversations with the ill child may be helpful in facilitating conversations with parents. Another helpful tool is Choices for My Child, which is a document from the United Kingdom originally developed for parents of children with neurological conditions where the child is unable to communicate his or her own treatment preferences.[43] This tool can be used as a way to consider where the child is now on the spectrum of a wide variety of domains of physical, emotional, spiritual, and psychological function and then compare this status over time at multiple time points to establish a trend of decline, stability, or improvement. Often reflecting back over time allows parents to have a "picture" of the trajectory of their child's illness. This may also be accomplished by asking the parents to describe what the child was doing in those domains of function at different time points (i.e., 1 week ago, 1 month ago, 3 months ago, 6 months ago, 1 year ago, etc.). Facilitating a conversation about the noted changes over time can lead the parents to better understanding (Box 61.6).

Box 61.6 Guidelines for the Healthcare Team to Use in Assisting Parents with End-of-Life Decision-Making

1. At the time of diagnosis and throughout treatment, actively seek opportunities to provide information to the parent about treatment and the patient's response to treatment.
2. At the time of diagnosis and throughout treatment, involve the parent in treatment-related discussions and decision-making. Be available to discuss and rediscuss decisions and related concerns.
3. Ask parents if they would like to talk with parents of other pediatric oncology patients.
4. Verbally and nonverbally reassure the parents that they are "good" parents who are committed to the well-being of their child and that they have made good decisions for the child all throughout the child's treatment course.
5. Provide assurances that everything that can be done to help the patient is being done and being done well.
6. As the child's disease progresses, provide clear verbal (and written, if desired by the parent) explanations of the child's status. Provide visual sources of evidence such as actual scans, with appropriate interpretations.
7. Inform parents of treatment options as they become available in the treating institution or elsewhere.
8. At each treatment juncture, ask the parents what they are hoping for and anticipate that they will have more than one hope.
9. Include more than one healthcare team member in end-of-life discussions with the parents.

(*continued*)

Box 61.6 Continued

10. When discussing end-of-life options with parents,
    a. Strongly emphasize the team's commitment to the patient's comfort and to providing expert care at all times.
    b. Offer professional recommendations.
    c. Describe how their child is likely to respond to each option (the child's physical appearance, ability to communicate, etc.).
    d. Give information about other support resources (ethics committees, social services, other healthcare professionals, etc.).
11. When discussing end-of-life options with parents, anticipate
    a. Parents' vacillation between certainty and uncertainty about the decision.
    b. Parents' need for clarification and additional information to resolve their uncertainties.
    c. Parents' need for practical information about ways to explain the end-of-life decision to other family members.
    d. Being asked to give personal advice (i.e., what you would do if this was your child).
12. Allow parents private time to consider the options.
13. Maintain sensitivity to any specific ethnic, cultural, or religious preferences during end-of-life care.
14. Convey respect for the parents' right to change decisions when clinically feasible.
15. Consider seeking an ethics consultation for the family and/or the healthcare team as a whole.
16. Consider seeking consultation from palliative care experts.
17. Demonstrate commitment to maintaining the child's comfort and dignity and to affirming the parents' role.
18. Do not question the parents' decision after it has been made.
19. Carefully document the end-of-life treatment or care decision once it is made so that all clinicians can be fully informed of this decision.

The Role of the Nurse in Decision-Making

Nurses are in a unique position to provide education and anticipatory guidance for the decisions that children and their families face throughout the trajectory of the cancer diagnosis and other serious illnesses. Nurses develop trusting relationships with children and families at the bedside, which creates an environment that empowers parents to make informed decisions and helps the child and family to transcend the experience of end of life with a peaceful death.[44] Accurate family education about side effects and interventions is essential to clarifying realistic expectations.

Nurses provide support for children and families at all stages of the cancer experience, from diagnosis through survivorship, end of life, and into bereavement. Providing empathetic listening, presence, and supportive care enhance the trusted relationship. Allowing children and families time to express their feelings and providing empathy for the family's point of view will aid the family in processing the information about the child's condition and in making immediate, as well as future, decisions. Nurses also provide realistic information about prognosis based on the clinical evidence, as well as their experience, to gently inform the family that a child is unlikely to survive. Hearing this information from a trusted member of the healthcare team may support the family's decision to forgo more aggressive medical and life-sustaining interventions. The expertise of nurses in facilitating and advocating for EOL decision-making conversations is helpful to elicit the child's and parents' voices in goals of care. The impact of nursing involvement in EOL conversations with patients and families may help families realize the patient is dying and make informed decisions regarding treatment options.

Support of Professional Nursing Organizations of the Nurse's Role in Decision-Making

The American Nurses Association (ANA) Code of Ethics[45] supports the nurse in advocating for the rights, health, and safety of all patients and families. Guidelines to support members of the healthcare team may be helpful to frame discussions with families and between the healthcare team (Box 61.6). The ANA has published position statements to guide nurses in participating in EOL decision-making, including "Nursing Care and Do Not Resuscitate (DNR) and Allow Natural Death (AND) Decisions"[46] and "Nurses' Roles and Responsibilities in Providing Care and Support at the End of Life."[47] These statements are not specific to pediatrics, however they do endorse developing an adequate skill set to facilitate discussions and encourage patients and families to actively participate in decision-making. The HPNA[13] advocates for a dynamic process in a series of conversations with families over time, beginning before anticipated health crises. The ANA and HPNA Palliative and Hospice Nurses Professional Issues Panel endorses the role of the nurse in facilitating informed decision-making for all patients with serious illness, including pediatric patients.[48] Advocating, supporting, and facilitating decision-making for children with cancer and their families is not only a professional obligation supported by key nursing organizations, but it is ethically our responsibility in providing high-quality child and family-centered care (Box 61.7).

Box 61.7 Guidelines for the Healthcare Team to use in Assisting Each Other with End-of-Life Decision-Making

1. Know the guidelines offered by specific disciplines regarding roles in end-of-life decision-making (i.e., the ANA's official statements on what the nurse is expected to do to help parents and patients make decisions) because it is possible that the guidelines differ from expectations held by others outside the discipline.
2. Before initiating end-of-life discussions with patients[a] and parents, all members of the healthcare team should discuss and agree on
    a. The need for such a discussion.
    b. Which options are appropriate and available.
    c. Whether outside consultants, such as an ethics committee, palliative care specialists or an external oncology expert, are needed to identify which options are in the best interest of the patient.
    d. Which other team members will participate in the discussion with the parents and patient.
    e. The time of the discussion and specific staff members who will participate.
    f. Which staff member will document the discussions in the medical record.
    g. Availability of the appropriate staff time and resources to address any questions parents and patients may have. Communicate to the team members who were not present at the patient-and-parent discussion what specific language was used to provide support to the parents and patient in making this decision.
3. Be available to team members and to the patient and parents to discuss and rediscuss decisions and related concerns.
4. Explore with the team all appropriate options to ensure that all that can be done is being done and being done well.
5. Consider consulting an ethics and/or palliative care expert on behalf of the entire team.
6. Inform other team members if feedback from or assessment of the patient, parents, or both indicates that any decision needs clarification or reconsideration.
7. Directly approach other team members regarding aspects of decision-making rather than seek such information from the parents.
8. Make certain that decision-making is fully documented in the healthcare record and accessible for all members of the team.

[a] When considering whether the patient should be present during such discussions, evaluate the developmental stage of the patient and the severity of illness and symptoms at the time of the discussion.

Conclusion

Decision-making in pediatric oncology is complex and dynamic, from the time of diagnosis throughout the trajectory of disease into survivorship or death and bereavement. Children and parents should be actively engaged in conversations that elicit their unique values and preferences. Healthcare providers must provide accurate and timely information to inform decision-making in a developmentally appropriate manner. This information should be reviewed frequently, framed in terms of the child's stable or changing clinical condition, and respect the opinions of parents as experts on their child. The child and family should be provided with opportunities for advance care planning, beginning before health crises. Nurses are key to advocating, initiating, and facilitating discussions with family that educate, inform, and elicit goals of care that honor the values and preferences of the child and family.

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CHAPTER 62

Palliative Care in the Perinatal Setting

Neonatal Intensive Care Unit, Labor and Delivery Unit

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Key Points

- Palliative care in labor and delivery (L&D) and the neonatal intensive care unit (NICU) is an integral component of family-centered care and patient-focused care. Palliative care gives nurses the opportunity to provide support for the infant and family unit at a time of tremendous stress. Care for an infant, either prenatally or postnatally, with a life-limiting or life-threatening condition is one of the most intimate times that a nurse can share with a family.
- Palliative care incorporates comfort care and pain and symptom management for the infant, as well as emotional, psychosocial, and spiritual support for the infant and family members. Family is defined by the parents or caregivers and may include other children, grandparents, and extended family members. Palliative care measures should be initiated early in the hospitalization and must be provided with cultural sensitivity and while supporting the developmental aspects of neonatal care. Palliative care is provided when a condition is life-threatening; this condition may or may not result in death. Palliative care can be provided along with curative treatments.
- Palliative care involves a dynamic exchange of information among an interdisciplinary team and the family and promotes the implementation of care that is aimed toward treatment of pain and distressing symptoms that interfere with the infant's and family's quality of life. The nurse has a compelling role in both prenatal and neonatal palliative and end-of-life care.
- In 2015, the infant mortality rate in the United States was 5.9 deaths per 1,000 live births and more than 23,000 infants died; the five leading causes of infant death were birth defects, preterm birth, sudden infant death syndrome, maternal pregnancy complications, and injuries.[1]
- Palliative care interventions and end-of-life care should be a part of the nurse's sphere of practice and requires that the nurse develop competencies in providing supportive and compassionate nursing care measures which can provide relief from emotional and physical suffering and bring about a peaceful death experience for the patient and family.[2]

Introduction

Substantial effort has been made to adequately address the need for perinatal and neonatal palliative care for patients and families. According to the American Academy of Pediatrics (AAP), pediatric palliative care (PPC) includes "relieving suffering, improving quality of life (QOL), facilitating informed decision-making, and assisting in the care-coordination between sites of care."[3] Due to technological advances in the past 30 years in diagnosing fetal anomalies and genetic disorders during the prenatal period, parents may face months of anguish and uncertainty as they prepare for the birth of an infant with a life-limiting, life-threatening, or lethal condition.[4,5] The sudden delivery of a prematurely born infant also may pose existential reflections within the family unit.

The anticipated delivery of a healthy term baby with a planned, predictable, and healthy future suddenly can become uncertain and overwhelming when the fetus is diagnosed with a life-limiting condition or the infant is delivered early or outside the viable gestational limits of medical and nursing knowledge and care.[6] Grandparents and extended family members often feel helpless and search for the "right things to say" to support the mother and father. Siblings often experience a deep sense of confusion during a time that was supposed to be filled with happy anticipation.[7] As the time draws near for the birth of the baby, each family member will individually transition through thoughts that pose more questions than answers, as they come to understand the long-term consequences of the infant's underlying condition, poor prognosis, and/or poor QOL.[8] The nurse is in the key position to provide support to bring the needed aspects of care together during this challenging time.

Early empathetic communication with parents to give detailed information prior to the birth of extremely premature infants or neonates with life-limiting conditions or uncertain prognoses is difficult but necessary in order to provide supportive care for the infant and family.[9] After delivery, the baby may receive care in the neonatal intensive care unit (NICU) or remain in the labor and delivery (L&D) unit in order for the mother and baby to receive care if the infant's death is more imminent, was a fetal demise, or died during delivery. Most neonatal deaths occur after the family and interdisciplinary team (IDT) decide to withhold or withdraw life-sustaining treatment.[10] Structured, evidence-based bereavement programs in NICUs have demonstrated efficacy and parental acceptance in many intervention studies. A longitudinal, prospective study incorporated parent interviews to explore the bereavement process of parents with critically ill infants; the findings support measures such as early intervention in preparation for the possible death of an infant and establishment of resources to prospectively support parent bereavement, including memory-making.[11] Nurses should recognize the sensitive nature of this subject and use language to promote a culturally sensitive, patient- and family-centered approach to the care of the infant during this difficult time for the family.

Parents are often faced with challenging decisions and even some uncertainties regarding the impact of shifting their focus from curative therapies to palliative care measures.[12] Providing a seamless transition into palliative care measures requires an interdisciplinary effort and support of the entire healthcare team. The focus of the team should be to provide optimal conditions for the infant's life and death, including interventions to prevent and relieve suffering.[12] Implementing a palliative care protocol involves tremendous individual planning that supports a variety of choices, which may include various aspects of active life-sustaining measures, up until the end of the infant's life. The nurse has a vital role in ensuring that communication with the family is not fragmented and that parents are reassured that the best effort will be made to support their wishes throughout the uncertainty of the journey. Dignity of the infant and family should be maintained at all costs.

Patient- and family-centered care measures seek to ensure that the final hours of a dying infant are spent in a peaceful environment and in the presence of the family. This chapter presents the core values of perinatal and neonatal palliative care nursing within the context of providing culturally appropriate, compassionate, individualized, family-centered developmental care (IFCDC) and patient-focused care for infants receiving care in the L&D as well as in the NICU environment. To illustrate use of palliative care with the neonatal population, the following case study was supplied by a parent.

Case Study: Just Breathe: Graham's Story

by Christy McGurgan

"Our son Graham was born by emergency C-section at 24 weeks, weighing 1 pound 2 ounces. When I entered Graham's room for the first time, I couldn't find him among the tubes and tangle of wires in the incubator. I couldn't believe how fragile he looked. His body was so thin, I could have wrapped my thumb and middle finger around it. His chest pulsed up and down with each heartbeat. I tried to catch my breath, I had to remind myself just to breathe.

"The next day, Graham had a pulmonary hemorrhage, and was placed on the high-frequency jet ventilator. He looked like he was having a constant seizure, his entire body was shaking. It was hurtful to look at my baby that way, I found myself holding my breath again as I watched. His nurse suggested that I take some of my pumped milk and put it on Graham's tongue, and with that simple suggestion, she empowered me to take care of my baby. After 2 days of helplessness and crying, this was the first thing that I could do to help him, and I was extremely grateful.

"When Graham was about a week old, he developed an unidentified black spot on his back. Before it could be diagnosed, it spiraled out of control, and, in just a couple of days, it had spread through his skin, muscle, tissue, and bone. After several days, it was diagnosed as an extremely rare and invasive fungal infection. It was so rare that only 70 cases had been seen in 50 years. We couldn't amputate because the infection was in Graham's back. At that point, the neonatologist took us into a quiet room. He was very patient, slow, and respectful. He told us, "We don't know how much time you have left: maybe a couple hours, maybe a couple days." He paused, then added quietly, "I recommend you spend as much time with him as you can." No words could come out of my mouth. We had no idea what to do. Fortunately, the doctor's quiet demeanor, his patience in allowing us to take in the information, and his recommendation gave us a place to feel safe and gently guided us to our next step. From that point on, we didn't focus on anything except being with Graham. Our goals were bonding with Graham, giving him love, and making him part of our family. Despite what the doctors told us, when his wound was covered, he looked like a "regular" micro-preemie. We vowed that we would follow Graham's lead. If he showed us that he was ready to die, we would let him go. If he showed us he wanted to live, we would support his fight for life.

"Medical staff orchestrated a plan for me to hold Graham while he was on the high-frequency jet ventilator, despite NICU policy. The reason was clear: they didn't want Graham to die without me ever having a chance to hold him. Knowing this broke my heart, but I was intensely grateful for the opportunity to hold my precious baby for the first time at almost a month old. While the policy had been no holding babies on the high-frequency jet ventilator, the benefit that it brought to Graham and to me was huge, and I was extremely grateful to staff for overlooking the policy for the benefit of our family.

"Once we started medically treating Graham's infection, its progress halted significantly. Once I began holding Graham, he began to improve, and the neonatologist made a standing order that we could hold him as much as we wanted. We held him constantly, when we weren't in rounds or providing hands on care, and the hours that we were told Graham had left to live turned into days, then to weeks, then to months. The nursery let my husband and me take care of Graham in any way that we could, and helped his sisters participate in his care by allowing them to change Graham's clothes, hold his pacifier in his mouth, and even help with his physical therapy.

"Graham's nurses showed caring in many other ways: after I went home at night, they played a recording of me reading to him, sometimes put a blanket over me while I slept in a chair by his incubator after late nights at the hospital, and even sent Graham postcards in the NICU when they went on vacation. Despite the prognosis that he would die at 2 weeks, Graham spent 7 months in the NICU. He eventually overcame the infection. However, complications from the infection caused Graham to develop pulmonary hypertension (PPHN) and prevented his lungs from growing large enough to oxygenate his body as he grew.

"The night Graham's vitals started going downhill, we knew it was the beginning of the end. His nurse called our primary nurses, nurse practitioners, and parent support staff. They were our family, Graham's family. They had been with us all day every day for the last 7 months. They had taken care of him, laughed with us, cried with us. When we knew it was time to let him go, they left us alone with Graham, to say goodbye in private. My husband and I held Graham together, crying and comforting him, as he peacefully drifted off to join the NICU angels. Our NICU family helped us with hand and footprints, cut a lock of hair, helped us bathe him, and neatly packed away his treasures. They allowed us to move at our pace, to care for our baby in death as we had in life, to spend all the time with him we needed.

"That night, my husband and I said the hardest goodbye that we'll ever have to say, but what we gained from that time with Graham is so much more than we lost, and we couldn't say that without the support of Graham's medical team. With their support, we did every single thing we could to save our baby, we loved him intensely, we bonded with him, and we understood Graham enough to know when it was time to let him go. Every bit of support that we got changed all of our lives for the better forever, and my gratitude for that will never be enough to say thank you for what they did for Graham and for our family."

Summary of Graham's Case

The nurse must be present at the most difficult time for the family, to be fully attentive to the infant and family and to separate personal values regarding birth, life, and death from those of the family. Nurses must adapt and individualize the care so that there is as much support for positive development as possible for the infant and family. It is only after the parental role is solidified that parents can become caregivers to a child that may or will die. The main obstacles to good palliative care are the inability to appropriately communicate with grieving parents and a lack of knowledge about evidence-based pain management.

Standard of Care for Neonatal Patients

The care of the neonatal palliative care patient is not setting-specific. Care can be provided within the L&D unit, NICU, a newborn special care unit, or through a perinatal home hospice program.[4] Integration of perinatal and neonatal palliative care services in tertiary care centers is increasing in the United States and other developed countries. Importantly, early identification and referral of patients to palliative care teams are encouraged to provide comprehensive care.[8] For example, extremely premature infants with multiple comorbidities are potential candidates for early and consistent perinatal or neonatal palliative care. The nurse is instrumental in providing goal-directed support through care that integrates potential curative therapies with palliative measures. All patients may benefit from the palliative care goals of reducing suffering, minimizing symptoms, and improving QOL.[8]

Nurses work with the IDT to ensure that the patient and family have all needs addressed. To deliver care that is interdisciplinary, as well as patient- and family-centered, nurses work collaboratively with neonatologists, nurse practitioners, social workers, chaplains, child life specialists, geneticists, respiratory therapists, pharmacists, and many subspecialists.[8] The nurse often leads communication with the family and should participate in palliative care discussions as part of the palliative care team because the nurse spends the most time with the infant and family. A study reported the strengths and weaknesses perceived by parents in their communication with physicians and nurses in the NICU. The findings noted that communication with nurses was described as a source of emotional support more often than communication with physicians and that nurses, because of the nature of their job, are more often physically present at the bedside and thus more available for emotional contact with families.[13]

Parents and caregivers often voice concerns to the bedside nurse as they process difficult information about the infant's medical status. The neonatal nurse, with the support of the IDT, should be prepared to provide palliative care within the context of the infant's uncertain life trajectory. There are six key roles for nurses in providing palliative care. These are pain and symptom management, prenatal palliative care consultations, end-of life care, discharge to hospice, communication and conflict resolution, and collaboration in the care of the medically complex infant.[9] The nurse should work in collaboration with the IDT to support the needs of the family and utilize knowledge of standard ethical principles to provide a patient-focused and family-centered care (Box 62.1, Table 62.1).

Cultural Influences on Care

For culturally competent care to reflect the complexity of care that is much broader than ethnicity, the nurse must be sensitive to cultural, ethnic, and religious values. Importantly, parents must be asked whether they have personal cultural or religious preferences for the goals of care for their child. The terms "healing" and "suffering" have various meanings within the cultural belief system of each individual family. The nurse should not assume that because the family is of a particular race, ethnicity, or religious sect that their reactions or requests are reflective of all individuals of that race, ethnicity, or religious sect.[4] For example, bereavement

Box 62.1 Core Concepts of Patient- and Family-Centered Care

- *Dignity and respect.* Healthcare practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.
- *Information sharing.* Healthcare practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
- *Participation.* Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- *Collaboration.* Patients, families, healthcare practitioners, and leaders collaborate in policy and program development, implementation, and evaluation; in healthcare facility design; and in professional education, as well as in the delivery of care.

Source: Reprinted with permission from the Institute for Patient- and Family-Centered Care (http://www.ipfcc.org/), 2013.

Table 62.1 Palliative care medications for neonatal patients

Medications	Usual dose	Special considerations
For pain		
Morphine	0.02–01 mg/kg IV q2–4h PRN	Opioid. Medication of choice for pain management in palliative and end-of-life care
	0.2–0.4 mg/kg PO/SL q2–4h PRN	May use in combination with benzodiazepine
	Infusion: 0.02–0.1 mg/kg/hr	More frequent doses may be needed to assure patient's comfort.
Fentanyl	1–3 mcg/kg IV or Intranasal q1–2h PRN	Fast onset and short-acting opioid
	Infusion: 1–3 mcg/kg/hr	Use injection form to administer intranasally. Bioavailability is almost 90%.
		Preferred in patients with renal failure
Methadone	0.05–0.2 mg/kg IV or PO q4–24h	Long-acting opioid
		Usual starting frequency is every 8–12 hours scheduled.
		Peak onset is delayed and may require breakthrough pain medication for 48 hours after initiation or dose escalation.
Acetaminophen	10–15 mg/kg PO/IV q4–6h PRN	Analgesic. Antipyretic
	20 mg/kg PR q6h PRN	May give IV form undiluted over 15 minutes
	7.5–10 mg/kg IV q6h PRN	
Oral sucrose 24%	<1 kg: 0.1 mL PO PRN	Analgesic. May administer directly into mouth or apply on pacifier
	1–2 kg: 0.5 mL PO PRN	
	>2 kg: 1–2 mL PO PRN	
For pain/sedation		
Clonidine	1–3 mcg/kg PO q6–8h	Alpha agonist. Has mild analgesic and sedating properties. May cause hypotension and bradycardia. Avoid use of patch in neonates.
For sedation		
Midazolam	0.05–0.1 mg/kg IV q1h PRN	Very short-acting benzodiazepine
	0.2 mg/kg PO/SL or Intranasal q1h PRN	Anticonvulsant, sedating, produces amnesia. Rapidly penetrates the CNS.
	Infusion: 1–2 mcg/kg/min	During end-of-life care, more frequent doses may be needed to ensure patient's comfort.
Lorazepam	0.05–0.1 mg/kg IV/PO/SL q2–4h PRN	Benzodiazepine
		Reduces anxiety and agitation. Anticonvulsant
		Consider adding to opioids for sedation
Diazepam	0.05–0.25 mg/kg PO or PR q4–12h	Long-acting benzodiazepine. Peak onset is delayed and may require breakthrough with shorter-acting benzodiazepine for 24–48 hours after initiation or dose escalation.
		Reduces anxiety and agitation. Anticonvulsant.
		Consider adding to opioids for sedation.
For secretions		
Glycopyrrolate	2–10 mcg/kg IV/SC q6h 20–100 mcg/kg PO q6h	Decreases oral secretions through anticholinergic activity. Increase slowly to effective dose. Consider reducing dose if signs of tachycardia noted.
For constipation		
Glycerin suppository	1/8–1/4 suppository PR q12–24h PRN	Osmotic laxative. Consider using with opioids to reduce constipation.

Source: References 36–45.

interventions such as mementos (i.e., hand and footprints; lock of hair) or photographs of the deceased infant may not be acceptable in all cultures.

In an example of a nurse working with a Native American family, the nurse must consider how to combine healing ceremonies from tribal rituals, if that is what the family desires, with Western medicine to alleviate suffering. In this instance, ethnic and religious beliefs are intertwined. But, in other instances, religious and ethnic values must be differentiated and incorporated into individualized care. It must be remembered that not every family that identifies with an organized religion strictly adheres to all principles of that faith. The entire healthcare interdisciplinary palliative care team must guard against prescriptive, generalized, and oversimplified views of different cultures' and ethnicities' beliefs and practices concerning illness, suffering, and death.[14] Thus, individualized nursing care must include considerations of cultural assimilation, healthcare literacy and language barriers, educational attainment, health insurance status, and socioeconomic factors. Evidence demonstrates that, due to misunderstandings, lack of communication, and healthcare provider bias, racial and ethnic minorities (Asians, African Americans, Latinos) may have a delay in the initiation of palliative care services and pain alleviation as compared to white patients.[15] This delay or underutilization of palliative care measures may increase the infant's and family's pain and emotional suffering. The nurse needs to examine his or her own beliefs and biases because these personal constructs will influence the delivery of culturally sensitive palliative care.[14]

Neonatal Palliative Care Guidelines

The National Association of Neonatal Nurses (NANN) in 2016 published a position statement no. 3015 entitled "NICU Nurse Involvement in Ethical Decisions, Treatment of Critically Ill Newborns."[16] This position statement reiterates the importance of the contribution of the neonatal nurse on the palliative care team. In addition, the American Academy of Pediatrics published its recommendations in a guideline for care of infants, children, and adolescents in need of PPC and hospice care.[17] The guideline emphasizes the goals of PPC and the importance of collaboration among the IDT. Standards of care for patients in the NICU must be followed, and protocols for the implementation of palliative care should be guided by evidence-based practices.

Advocacy for Support Services

Nurses can serve as an advocate to ensure that comprehensive support is being offered to the family. The benefit of providing these services is crucial for the family unit to maintain a sense of "wholeness" as they journey through this challenging time. In order to best support parents in their role of decision-making, eliciting their values and goals is imperative; asking questions that explore a family's values, their understanding of the newborn's meaning and QOL, and their experience in the medical journey help build a relationship based on trust and caring. These measures support the need for adequate services during the neonatal end-of-life (EOL) care period.[16]

The nurse should not underestimate the impact that palliative and EOL care discussions can have on each member of the healthcare team. The nurse can feel torn between spending quality time with a dying child and family and caring for other patients. The emotional strain associated with end-of-life and bereavement care not only affects a nurse's health but can also affect relationships at home and with coworkers.[18] In the past decade, more attention has been paid to the role of the nurse and the sense of moral distress that can exist when a nurse is providing care for infants as they continue to decline clinically. The most commonly reported cause of distress for nurses is reported as having to follow orders to support patients at the end of their lives with advanced technology when palliative or comfort care would be more humane.[19] Parents may sense the moral distress when the nurse is not receiving adequate peer support during the delivery of intensive care measures. Initial distress involves feelings of frustration, anger, and anxiety when a person is faced with institutional obstacles and conflict with others about their own personal culture and values.[20] It is vital that nurses have a forum where they can process their concerns within a confidential and professionally supported environment.

The implementation of debriefing sessions or clinical case reviews for difficult neonatal cases can be helpful.[21] Team support can also come in the form of relief or "emotional rest" periods for the neonatal nurse; for example, a nurse who has experienced a recent neonatal EOL care case may benefit from having patients with more stable clinical trajectories for the next few patient care assignments. Education and support in nursing practice could be enhanced by supporting nurses to attend workshops and seminars on the topic of perinatal loss and bereavement care; incorporating discussions on supporting families, patients, colleagues, and oneself in bereavement care during orientation to the unit and ongoing education; debriefing after perinatal loss; and providing staff with a bereavement mentor.[21]

Perinatal Loss and Palliative Care in the L&D Unit

Perinatal palliative care includes the needs of parents who are faced with a life-limiting fetal condition that may present as death in utero or quickly following birth.[22] Perinatal loss encompasses loss during pregnancy through the neonatal period. Intrauterine fetal demise (IUFD) is commonly called a *stillbirth,* although birth of an infant at 20 weeks or greater gestation is considered a neonatal death in the L&D setting. "Perinatal death, although not always fitting the traditional palliative care referral criteria, results in grief and bereavement unique in human relationships. Regardless of the circumstances that surround the loss, parents are often devastated and heartbroken."[23] In the United States, according to 2013 vital statistics, fetal mortality at gestations of 20 weeks or greater occurs at a rate of 5.96 per 1,000 births.[23] *Perinatal mortality*, defined as fetal death at 20 weeks of gestation or greater *and* neonatal death at 28 days or less after birth, occurs at a rate of 9.98 per 1,000 births.[24] Given the incidence of perinatal mortality in the United States, it is imperative to have an understanding of palliative and perinatal bereavement care.

When first learning of a life-limiting condition or fetal death, parents are faced with multiple decisions to make in a relatively short amount of time. Patients experience overwhelming stress, shock, and grief as they must make decisions with many implications.[24] Decisions should be made with full knowledge and understanding of the situation as well as of options that may exist. When parents are given the poor prenatal diagnosis, the option of a perinatal palliative care program should be offered.[25] For families with a perinatal life-limiting condition or for those going through unexpected loss, the L&D unit becomes a palliative care unit. The goals of care in these circumstances are to help families face the diagnosis, listen to and discuss options as the family is ready, and facilitate communication with providers and other ancillary team members, as well as being present while the family experiences a situation like no other.[25] The parent may learn of the life-limiting condition at a prenatal visit and have months to plan and anticipate the birth of the baby. In the months leading up to birth, time can be spent deciding on wishes for the pregnancy and birth. Birth plans can be developed outlining specific wishes related to L&D

care (both antepartum and postpartum) and palliative care photography.[25] Parents often make statements such as, “just let my baby be born alive,” with a desire to spend every second possible with the newborn regardless of how short life may be. Others have unexpected complications and have minutes to hours to work through decisions that can impact the life trajectory of the newborn. For those with unexpected complications, the same decisions must be made quickly and are often made while in a state of disbelief.

Perinatal palliative care involves caring for the mother, her unborn child, and the family during the antepartum, intrapartum, and postpartum periods and actively participating in bereavement care planning prior to and after birth.[25] Flexibility is needed when working with families experiencing perinatal loss because parental decisions can change. Nurses are on the front-line and are with the parents at time of diagnosis and delivery, as well as providing bereavement care. Focusing on the L&D setting, an overview of perinatal palliative care and bereavement support will be discussed as we follow a family that experienced an IUFD.

Case Study: Perinatal Palliative Care

Crystal and EJ were expecting their third child. Crystal (an L&D nurse) was 36 5/7 weeks pregnant, and she named the baby Norah Raine. After working her 12-hour night-shift, Crystal did not feel Norah moving like “normal.” She went to L&D triage for evaluation prior to going home. Per routine, the L&D nurse in triage placed Crystal on the fetal heart monitor. No heartbeat was detected. The physician was notified and came to Crystal’s bedside, where an ultrasound showed that Norah no longer had a heartbeat.

Crystal Shares Her Inner Experience

“There is a feeling as mothers that we want to protect our children from harm. I felt profound powerlessness, guilt, and defeat. I had never had an epidural with my previous deliveries but decided to get one because I wanted to somehow distance myself from the birth. I felt so strong and connected to the process of delivering my boys. This time, I felt weak and powerless. I hoped the doctors were wrong. I hoped the moment I held her in my arms a miracle would happen, and she would begin to cry. Norah Raine was delivered at 1:15 P.M. in a room full of silence after two easy pushes. I will never forget the doctor who delivered her, holding her lifeless body and looking at me to say, ‘I am so sorry,’ before he laid my daughter on my chest. Those first moments seem a blur, busy with activity to complete the delivery. My placenta was delivered, the bed was reassembled, all the while I held and took in every corner of her face. We laid her on the bed and admired every tiny detail, as I wanted to never forget how perfect she was. There were minor imperfections of peeling skin which I knew was to be expected, but in my eyes, all I saw was my beautiful, perfect first-born daughter. My nurse was instrumental in leading us through next steps. We gave Norah a bath, brushed her soft brown hair, and dressed her in the nightgown and blanket we had planned to bring her home in. It felt good to care for her in a way that felt normal. We created footprints, handprints, and took a lock of hair for her memory box. A photographer was called from a local organization and arrived to take precious photos of Norah and us together. Later we invited our other children and parents to meet and hold their sister and granddaughter for the first and last time. We chose to keep Norah with us through the night. We were placed on the gynecology unit. Once we released Norah to the funeral home, I was discharged home, with empty arms. The days and weeks after the loss of Norah seemed to drag on endlessly. My doctors called me to check on us, my friends from the unit called and visited, and many sent cards and flowers to our home. The outpouring of love from family and friends kept us from drowning in those early days. Local support groups and friends who were willing to listen were all instrumental in helping me to walk through the journey after the loss.”

Summary of Crystal and EJ’s Experience

Supporting parents as they find out their baby has died or will die immediately after birth can become a humbling experience for the nurse. The nurse may have a sense of powerlessness while seeking to become empowered to help support the patient and family. It is the nurse’s role to help the mother through labor and to remain present when the parents face the challenge of saying goodbye to the newborn. Many parents hope that the diagnosis is wrong and that their baby will live. For those patients with previous knowledge of life-limiting conditions, a L&D plan is created with a multidisciplinary team.[25] Questions are centered on the labor process, what to expect, and fear of the unknown.[26] For those in preterm labor or diagnosed with an IUFD, decisions are often made quickly. Preterm labor may lead to several stressors; for example, the patient may be transferred to a large tertiary care center that is located many miles from home and away from their usual care provider as well as from family and friends. The patient hopes that her labor will not happen prematurely; however, that hope often turns to sadness as delivery becomes inevitable.

A vaginal delivery is preferred since a cesarean section is major abdominal surgery with its attendant increased risk, including for patients who have had a previous cesarean delivery.[26] The focus of fetal monitoring changes to observing contractions. If the fetal heart rate is monitored and there are signs of fetal distress, there can be preparation for cesarean section. In the case of an IUFD or a baby with a life-limiting condition, induction of labor can occur with cervical dilation and delivery. Induction options may include cervical ripening with medication, a mechanical option such as a cervical balloon, or induction without cervical ripening. Time in labor can vary greatly and may be prolonged up to several days depending on the dilation of the cervix at the beginning of the process and the normal variables of labor.

The pain of labor is always challenging; however, without the hope of a “normal” baby, the pain often seems intensified. Patient teaching and perinatal palliative and bereavement care begins with admission and continues through discharge and beyond. Answering questions about the labor and birth process and what the baby will look like becomes the focus during labor. During labor, patients who have a fetus with a deformity or IUFD are often waiting anxiously and have fears about the appearance of the baby. Nurses should create a supportive and open environment for questions, concerns, and fears. After delivery, the teaching focuses on self-care, family grief, community resources, and infant disposition.[26] Some parents and family members fear seeing a deceased, damaged, or deteriorated body.[27]

Nurses should be honest and compassionate when explaining what parents should anticipate. An IUFD, for example, may have peeling skin and pale skin tones. Blankets and clothing can cover any area of the skin that may not be intact. Deformities and congenital syndromes often have characteristic traits that can be described to prepare the parents and family for the baby's appearance. Prior to delivery, the patient and family should discuss their expectation about social media posts, photographs on cell phones, video, cultural rituals, or desires with their caregivers, family, and friends. The focus of the nurse includes medical care such as induction medication management, pain control, and comfort measures, as well as encouragement and reassurance.

At times, the delivery room can become chaotic as staff prepare for possible resuscitation and parents hold on to hope that their baby will live and will have the option for transport to the NICU. Once the baby is born, decisions are made quickly whether to start, continue, or discontinue life-saving measures. Anxiety can be overwhelming for the family. After members of the delivery team have completed the delivery process, there is a plan in place to allow for the family to have privacy. It is the nurse who remains with the patient and family, giving care to the dying or deceased infant as well as to the mother. The birth of a baby with life-limiting conditions in which parents have chosen to avoid resuscitation or an IUFD requires consistent interdisciplinary support. Family presence is at the discretion of the parent(s). The delivery room is often somber and peaceful, with hushed voices. There is a silence in the room as the baby delivers without that hallmark cry of a normal newborn. Parents may weep quietly and hold their baby or they may not appear sad at all; while looking at the baby they may talk about any familial features of the baby while enjoying their moments together.

Parents experience several first moments with the baby, the first moments of life and/or death, the first look, touch, bath, and dressing, as well as the last moments including the last look, touch, bath, and dressing. All the hopes, dreams, anxieties, and anticipation of the possibilities that will come with new life are changed to a new set of fears, anxieties, hopes, and heartbreak. The nurse is often present with parents around the time of the death.[28] The nurse must help the patient and the family navigate through this time while displaying compassion, understanding, presence, and patience. It is common for families to ask the same questions repeatedly. The nurse becomes the mediator, giving families privacy, having side conversations (with permission) with the extended family, answering questions, listening, and being present. Care should emphasize the importance of the baby. The nurse role-models the handling of the deceased baby for the patient and family, which can help the patient and family to feel more comfortable in handling the baby. The nurse should call the baby by name if possible and point out all the good things about the baby (i.e., cute nose, perfect hands, etc.).[29] If agreed to by the parents, collect and create mementos like a lock of hair, pictures, footprints, molds of the hands or feet, and allow the parents to take as much time as they desire.[30]

Postpartum care for the patient is the same from a medical standpoint. Perinatal loss resources and education on what to expect are imperative in the postpartum period. The loss of a baby does not shorten or change the physical and emotional changes that occur after pregnancy ends. Nursing assessments include observations of the perineum, fundus level, bleeding, and breasts. Postpartum care should be taught and reinforced.[26] Lactation support should also be discussed, as some women may choose to suppress their milk supply while others may choose to donate their milk to a milk bank in memory of their baby.

The family members are also grieving. The nurse may encounter fathers in hallways and waiting rooms seeking to regroup emotionally. The nurse should be open to listening and comforting. Fathers can also develop posttraumatic stress disorder (PTSD) and depression.[31] Siblings can handle grief differently, and their developmental stage impacts their ability to comprehend the situation. Not acknowledging the death and the subsequent grief of the sibling may complicate that child's grief. Grandparents are often struggling with their own grief. Discussions need to occur with the patient and family as to how the patient wants to handle the potential newborn nursery at home and baby shower gifts, as well as funeral arrangements. Notification of friends and acquaintances may or may not happen due to the extent of grief, and, in turn, family friends may unknowingly ask about the deceased baby weeks later.

Perinatal loss resources should be given to the patient and family that allow connection to others experiencing the same loss.[26] The nurse forms a bond with the family that is rarely forgotten and is often celebrated at annual events to remember those who were born silent or had a very limited life.[31] For some patients, the pregnancy and birth will be their first or only pregnancy. For those who decide to have another child after loss, pregnancy and delivery can be challenging. The patient may experience an uncomplicated pregnancy the next time or could have miscarriages and experience loss again. Anxiety has been found to be higher in pregnancies after a perinatal loss, as well as increased rates of PTSD and depressive symptoms.[32–34] Formal and informal support networks from friends, families, and groups such as a church congregation often increase the resilience of mothers and lead to decreased symptoms of PTSD and depression.[34] Patients react differently to loss, and some may choose a different obstetrical provider, hospital, and nurses, while others might want everything to stay the same.

New Trends

In 2003, the End-of-Life Nursing Education Consortium (ELNEC) developed a neonatal/PPC curriculum.[35] To date more than 1,800 pediatric/neonatal nurses have received this education in the United States and abroad http://www.aacn.nche.edu/elnec.

More institutions are interested in neonatal-specific content to start their own palliative care teams. Despite support from the AAP and the World Health Organization (WHO) for the provision of palliative care, there are still many barriers. Some barriers to neonatal palliative care include formal educational needs on the part of staff, a feeling of failure (especially by the physicians), difficulty in communicating bad news to the parents, and ethical conflicts among the team members.[23] The ability of the nurse to deliver care to the dying newborn is impacted by many barriers to and inconsistencies in such care. There is demonstrated evidence through the interest in ELNEC that nurses around the world wish to provide good palliative care as a standard part of neonatal and pediatric care.

Conclusion

Neonates with a life-threatening anomaly or illness and their families will benefit from timely and interdisciplinary palliative care. The nurse should focus on providing care when the prognosis is uncertain, and this may challenge existing healthcare system structures. The neonate's illness trajectory can be unpredictable, and the nursing focus needs to be on excellent pain and symptom management while promoting developmental care of the infant as well as maintaining culturally competent emotional, psychosocial, and spiritual support for the family. Families and healthcare professionals have the difficult task of helping the infant live as fully as possible with complete dignity and comfort while preparing for and accepting that the infant may not live a long time. This requires a committed IDT with referral to community resources as appropriate. Nurses new to palliative care practice should have the support of more senior nurses and staff because the first experience of infant death can cause a considerable amount of anxiety and emotional distress for the nurse.

Regardless of the length of life or the place where that life is lived, excellent palliative care includes optimum symptom relief for the neonate, honoring the parents' wishes, providing ongoing support to parents and family, planning for the death, and honoring the life by creating memories of that life. The nurse should avoid phrases such as "withdraw care" or "nothing more can be done." There are always interventions that can be done to promote comfort during the EOL care for infants with complex, life-limiting, or chronic conditions, such as supporting comfort measures, managing secretions, minimizing sleep disturbances, administrating medications for agitation, and optimizing the time the infant can spend peacefully with the family. Table 62.1 lists common medications used for the palliative and EOL care period for infants. The use of a neonatal scale should continue during EOL care.[16] Supportive care should continue throughout the bedside postmortem care and incorporate options for obtaining mementos. The website www.PerinatalHospice.org is an important international clearinghouse of information for providers and parents. The website was started in 2006 by Amy Kuebelbeck, a journalist and parent advocate. To date, 280 PPC programs representing 22 countries are listed on the website.[36]

In some areas, there are bereavement photography specialists who can assist with providing compassionately developed photographs of the deceased infant, such as the Now I Lay Me Down to Sleep organization (https://www.nowilaymedowntosleep.org/find-a-photog/).

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CHAPTER 63

Grief and Bereavement in Perinatal and Pediatric Palliative Care

Rana Limbo, Kathie Kobler, and Betty Davies

Key Points

- Bereavement care for all family members is an integral component of perinatal and pediatric palliative care.
- Grief assessment begins at the time of diagnosis of a child's serious illness, applies to all family members, and continues into the bereavement period following the child's death.
- Grieving after a death is a normal process because grief is experienced from the loss or alteration of a close relationship; however, some grief reactions become complicated, and nurses must assess for factors that put family members at risk for such reactions.
- Nurses have a responsibility to create supportive relationships in which family members feel free to express their grief.
- Caring for children at end of life requires nurses to attend to their own personal and professional responses to death, dying, and bereavement as a basis for providing optimal care to families.

Grief and Bereavement Overview

Effective and compassionate care for children with life-threatening conditions and their families is an integral part of care from diagnosis through death and bereavement follow-up.[1] The progression of such care has been summed up this way: "Grief flows from relationship. Relationship forms a bridge from suffering to hope. Hope transforms."[2] Guidelines and standards outlined by the National Consensus Project on Palliative Care, the American Academy of Pediatrics, and the Institute of Medicine emphasize the importance of providing interdisciplinary bereavement support to families experiencing the death of a child.[3–5]

Medical science has contributed significantly to the treatment of life-threatening illnesses or conditions, but children still die as a result of disease progression, extreme prematurity, trauma, and more. Grief can arise at any point in care for all connected in relationship with the child, even well before death occurs. Regardless of the cause, the death of a child is a tragedy, an incomparable life event that affects all family members, friends, and their community. A child's death also affects the physicians, nurses, social workers, and other healthcare professionals who provide care through the child's living and dying.

The purpose of this chapter is to discuss grief as a life-long, relational process. The trajectory of grief reflects how survivors of loving relationships maintain closeness and connection, cherishing dear ones, from those not yet born through adolescence, who are no longer physically present. Practical strategies for grief assessment and supporting bereaved parents and children are highlighted. Also included are the experiences of healthcare professionals as they maintain relationships with the child, the family, and team members and are affected by loss.

Grief as a Process

Death is a part of each individual life, something we all must face as we contemplate our own mortality. The expectation is that children will outlive their parents; the death of one's child is outside of that hoped-for pattern. The grief associated with a child's serious illness can begin at diagnosis, as parents and family members grapple with the possibility that the illness cannot be cured while also simultaneously hoping for a good outcome.[6] The Integrative Model of Curing and Healing[7] in Figure 63.1 shows bereavement and hope as intertwining experiences throughout a serious illness, accompanying the moments that make up each day. As a serious illness progresses, a realignment of goals occurs (termed "regoaling" by Hill and colleagues[8])—a result of shifting hopes and preferences in response to a child's deteriorating condition.

When a child transitions to dying, grief responses intensify, and family members' grief continues long past the child's death. Many parents feel that they never recover from the death of their child. They may resume daily activities, adjust to life without their child's presence, and find new pleasures in life, but most parents feel vulnerable and that they are not the same people they were before the child's death.[2] The death of a child, or any beloved person, is not something one gets over; rather, as time unfolds, one learns to integrate the loss into one's life. Indeed, grief is a process that is not always orderly and predictable; each individual's unique experience of loss is manifested in diverse ways.

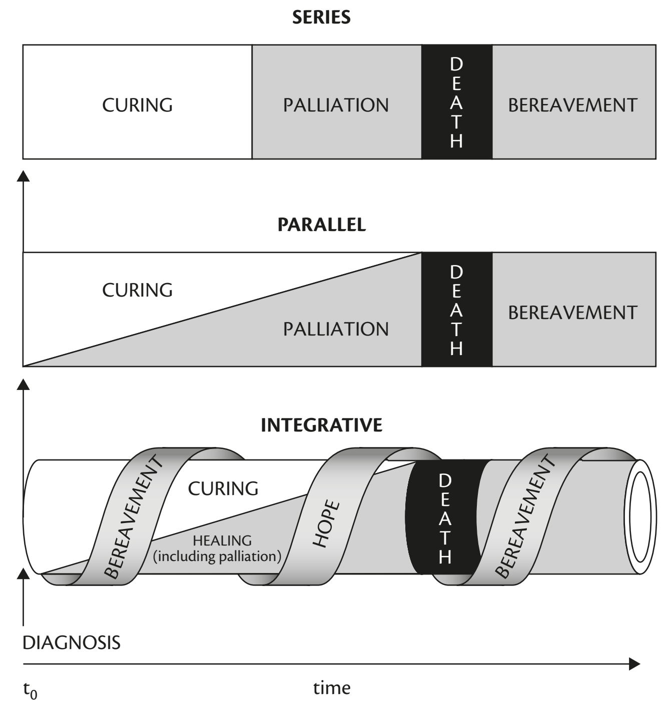

Figure 63.1 Integrative model of curing and healing (with bereavement and hope).

Source: Jay Milstein, copyright 2010. Modified by Rana Limbo and Kathie Kobler. Used with permission.

Grief, Bereavement, and Mourning

The term *grief* is used to refer to the emotional response to a loss.[9] But grief is much more than emotion. It is an overwhelming and acute sense of loss and despair. It is the personalized feeling and response that an individual makes to real, perceived, or anticipated loss or death. Grief encompasses every domain of human life: physical, emotional, psychological, social, and spiritual. Sadness, anger, numbness, sleep and eating disturbances, inability to concentrate, fatigue, existential angst, and tension in interpersonal interactions are among the responses to a loved one's death. Please refer to Table 63.1 for a summary of types of grief.

Grief occurs when an individual experiences a loss that he or she deems personally significant. To a certain degree, who or what we consider to be personally significant is culturally defined. For example, in the contemporary United States, the death of one's child is expected to result in profound grief.[13]

The term *bereavement* refers to the state of being bereaved or deprived of something. The word derives from the Old English word *reave*, which means to plunder, spoil, or rob.[9] This meaning implies that the lost object is a valued one (i.e., why someone who is bereaved feels deprived). This definition is especially apt for bereaved parents, who often report feeling as though a part of them has been torn away or that a part of them is missing. As the bereaved mother of a 22-month-old who died following a brain aneurysm sighed: "When my son died, it was as if my heart had been stolen from my breast, and my arms that held him ripped from their sockets."

Please refer to Table 63.2 for a summary of terms and phrases that help to understand grief and bereavement.

Mourning refers to the outward, social expression of grief—often through ritual—and sometimes to the psychological process of adapting to loss.[17-21] Expression of loss is dictated by cultural norms, customs, and practices, including rituals and traditions. Some cultures are very emotional and verbal in their expression of loss, while others appear stoic and businesslike. Religious and cultural beliefs and customs may also dictate how long one mourns and how one behaves during the bereavement period. In addition, outward expression of loss may be influenced by the individual's personality and life experiences.[22]

Grief in the Context of Relationship

Without relationship, there would be no grief; we grieve because we are connected in meaningful ways through relationship, which death significantly changes.[2] Parents, grandparents, siblings, healthcare providers, and all who cared about the child are affected when death occurs. These next sections reflect the ways relationship influences and is influenced by grief, no matter the child's age.

Child and Parent

Parent–child relationships are sacred, unique, and complex. The connectedness between parent and child has its roots in the biological and emotional bonds that precede birth. It grows as the parent begins to know and care for the child. The child is a parent's

Table 63.1 Characteristics of various types of grief

Type of grief	Characteristics
Anticipatory	Most commonly refers to situational factors that lead to grief for what might happen. A life-threatening diagnosis may lead to grief for a "normal" life. Thinking in terms of lost expectations helps one understand anticipatory grief. Often results in an "emotional roller coaster." Anticipatory grief is often accompanied by changing hopes.[9]
Disenfranchised	Acknowledges social context of grief. May overlook someone who has a close and intimate relationship with the one who receives bad news or dies. Often accompanies grief around stigmatized circumstances such as suicide, termination of pregnancy, or an early pregnancy loss (miscarriage). Young children or those with cognitive challenges may also experience disenfranchised grief if they are not expected (and therefore not allowed) to grieve.[10]
Complicated or Troubled	Complicated grief refers to a response to loss that is more intense and longer in duration than usual. It may also include prolonged searching and yearning. Examples of causes include chronic, suppressed, child death; stigmatized death; ignored response; a difficult relationship; multiple losses occurring close to each other; absent or very weak social support.[11]
Traumatic	"Traumatic" depends on individual perceptions and experiences; however, these types of death are generally more traumatic than others: death of a child (at any age), homicide and other violence, suicide, severe accident, disaster-related (terrorism, weather-related, fire). These examples are not prescriptive, but research findings show that traumatic deaths resulted in different ways of finding meaning and making sense of the death and the world than did deaths for which one could prepare.[12]

Table 63.2 Terms and phrases that help understand grief and bereavement

Terms and phrases (including theories, models, concepts, and other)	Explanation or description
Concept of perinatal bereavement	Groundbreaking work that expands the field of perinatal bereavement (PB). The authors conclude the following points: (a) phenomenon is universal, (b) follows perinatal loss, (c) lacks conceptual clarity, (d) addresses the need for scholarly study to clarify and extend perinatal bereavement as a concept. PB is a practice-based concept and may be confabulated with grief and bereavement. One clear meaning of the definition is that it follows *death*. Therefore, the authors concluded that the meaning of PB is "loss of a pregnancy or loss of an infant through death" (p. 4) (e.g., excluding infertility, traumatic birth, adoption).[14]
Caregiving theory	Comprised of four crucial functions in the area of perinatal bereavement: Nurturing, protecting, socializing, final acts of caregiving.[15]
Continuing bonds	The concept of continuing bonds addresses the idea that death does not end a relationship. In fact, the feeling of connection and affection remains forever in healthy grief.[16]
Regoaling	In their chapter on hope, hopefulness, and pediatric palliative care, Hill and Feudtner link hopeful thinking to goals. Specifically, they hypothesize that parents whose child has a life-threatening condition who hope for positive adaptation revise or establish new goals or set of goals (i.e., regoaling).[6]
Pridham's Guided Participation (GP) theory	GP is a theory of relationship-based teaching and learning researched over approximately 40 years specially bringing participatory learning into pediatric nursing. It has been adapted for use by interprofessional disciplines in clinical care by Karen Pridham, PhD, RN, FAAN.[18]
Dual-process model of grief	The authors suggest that grieving is a dual process of coping: restoration-oriented and loss-oriented. Some may describe this process using the metaphor of a roller coaster: at times, one may feel "normal," with merely a faint hint of the suffering following the death of a loved one (restoration-oriented coping). At other times, one is overtaken by grief, and memories of the person's life and death flood one's being, leading to loss-oriented coping. As time passes and the loss becomes more fully integrated into a person's life, suffering is less common.[19]
Empty space phenomenon	Parents were interviewed 7–9 years after the death of their child to cancer. They all identified an empty space and used three principal ways of filling it, with one example given for each type of responding: (a) getting over the loss (view themselves as not significantly changed), (b) filling the emptiness (periodically experience the empty space, but focus is about moving on to other activities and thoughts), and (c) keeping the connection the (definition and what the empty space constitutes changes over time). Findings suggest the experience of having a child die from cancer is dynamic over time and bears a conversation when the nurse has future contact with the couple.[20]

link to the future.[23] Tributes to the parent–child relationship appear regularly on social media. Recently, young parents whose first baby was diagnosed with several life-threatening conditions wrote so lovingly about the joy their unborn daughter already brought them at 20 weeks' gestation. She had a name, a place in their family, and their post was filled with descriptions of her movements and fighting spirit. They wrote of welcoming her to their family, whether she was alive at birth or not.

Watching a child become sick and die is a crisis of meaning for families, and it is through their cultural understandings and practices that families struggle to explain and make sense of this experience.[24] Results from one study[25] showed that parents whose child died of a nonviolent cause were more likely than those whose child died in a violent way to come to an understanding and make sense of the child's death more quickly. Gender, culture, temperament, and a variety of other factors influence grieving styles. Many parents whose child is receiving palliative care are likely having their first experience with illness, hospitals, medical technology, dying, and death. Consequently, they may have few practiced skills for dealing with significant loss.

Parental grief is all-consuming, affecting every aspect of the parents' existence. Parental bereavement after a child's death involves a level of suffering for both parents. Caution is advised against assuming that mothers express their grief one way and their partners in another. Both parents should be assessed individually to determine how they make sense of their loss. Parents often struggle with guilt throughout their child's illness and following death because of deep-rooted feelings of responsibility for their child's welfare. Parents are responsible for protecting and sustaining their children[26] and shielding them from all danger; many parents feel they should have protected their child from illness and death. When children die from an inherited disease, such as cystic fibrosis or sickle cell anemia, parents know that their child's condition results from their unknowingly passing on the genetic material.[27] When the child dies, parents may still carry the burden of knowing that their genetic makeup is responsible for their child's terminal illness. Parents whose child dies from an accident may also feel guilty for abdicating their protective role.

Bereaved parents may cling to irrational guilt because it is often easier to accept blame, with its fantasy of control, than it is to accept the total loss of control with which they must grapple. For example, one young mother's intense guilt was rooted in her belief that her baby's premature birth and eventual death was caused by her eating too many spicy foods early in her pregnancy. Parents may also blame someone else for their child's death. Sometimes this guilt is targeted toward a partner or spouse, or toward another child or family member. Nurses should be aware of these dynamics and help parents find an appropriate place for their anger and blame.[26]

Professionals who support bereaved parents are attuned to parents' own descriptions of being different after their child died. Gilmer and colleagues[28] found that changes in bereaved parents occurred primarily in two realms: in their personal lives (e.g., emotions, beliefs, work habits) and in relationships. Parents themselves reported changes in priorities, while their surviving children noted the intensity of their parents' sadness. Davies and Limbo[29 (p.78)] share the story of a mother who asked her college-age son, "Did I change?" Her son was in grade school when his brother—and, a year later, his sister—were stillborn. Her son was flabbergasted that she was not aware of how different she was from the way she had been before the loss of her babies. He responded, "You were never happy, you stopped being a room mother or participating with any of our sports teams. You cried all the time."

Researchers have found that the loss of a child affects the parents' relationship. Odds of divorce are higher in couples after miscarriage or stillbirth,[30] and the rate of relationship dissolution after such a loss increases for both married and cohabiting couples.[31] Researchers have also highlighted unique interpersonal dynamics between partners. Stroebe and colleagues[32] found that bereaved parents who attempted to hold in their own grief in order to spare their partner increased their own and their partner's grief over time (at 6, 13, and 20 months post-death), a phenomenon they refer to as "partner-oriented self-regulation (POSR)."[32 (p. 395)] Nurses who work with bereaved parents often hear one parent or the other make a comment such as, "I feel like I need to be strong for her" or "If he sees how I'm hurting, I don't think he can deal with it." The paradoxical nature of the findings from this study provides nurses with insight into couple dynamics, follow-up interventions, and potential support group topics.

Nurses must also be cognizant of the special needs of those bereaved parents who cope with additional stressors in their everyday lives. Moreover, nurses should pay attention to the indirect grief of parents who witness or co-experience the death of other terminally ill children in the same clinical setting as their child. Single parents or same-sex parents may not have as many options for support as married parents in a heterosexual relationship. Black and Fields[33] provided several clinical practice guidelines for nurses and others caring for lesbian couples who experience perinatal loss. Examples included recognizing the complexity of always needing a third party to get pregnant; understanding the financial, legal, and social ramifications of achieving the pregnancy; and considering that the couple may feel disenfranchised in their bereavement by those who judge their lifestyle choices. Same-sex couples whose baby dies appreciate being treated as any bereaved couple, not considered "different" or "unusual" as they navigate factors associated with their pregnancy and subsequent loss.

Child and Grandparents

The grief of grandparents is twofold: they grieve the loss of their grandchild, but they must also bear witness to the grief of their own child, the parent of the deceased child, a phenomenon termed "double pain."[34] In addition, grandparents experience cumulative pain.[34(p. 170)] Gilrane-McGarry and O'Grady identified three sources in addition to the double pain: pain from their own past losses, pain common to all grief, and witnessing negative changes in their child. Grandparents identified two factors highly relevant to nursing care that helped them with their grief: having their loss acknowledged and being considered a part of the bereaved family.[35] Nurses should hold in mind that grandparents will have their own unique needs in the moments surrounding their grandchild's end-of-life (EOL) care, especially if they experienced the death of another of their own children many years prior.

Grandparents can be a source of considerable strength for parents and siblings, or they can be an additional source of stress. Their advice may be sought but then ignored; often their practical help is accepted, but their own grief is barely acknowledged.[1] Grandparents may experience considerable helplessness and frustration; they question the meaning of life as they struggle with the lack of order they feel in having their young grandchild precede them in death.

Impact of Family Dynamics on Relationship

Families have characteristic ways of being in the world, of solving problems, of managing crises, of interacting with one another, and of relating to those outside the family. When a child is seriously ill and dies, families respond in the ways that are typical of how they manage other life events. These ways of coping are more or less functional. Past experiences with death and the learned response to loss also affect how each family member will grieve a child's death. Other deaths of a similar nature may have occurred in the family, such as when more than one child suffers from the same life-threatening genetic disorder or when grandparents experienced the death of their own baby years ago. How previous losses were handled in the family will influence the current situation.

Researchers of families with adult patients[36] and with pediatric patients[37,38] documented eight dimensions of family functioning: communicating openly, dealing with feelings, defining roles, solving problems, using resources, incorporating changes, considering others, and confronting beliefs. These dimensions occur along a continuum of functionality, so that family interactions tend to vary along the continuum rather than being positive–negative or good–bad.[37]

In families where thoughts and opinions are expressed freely without fear of recrimination, where a wide range of feelings is expressed and differences tolerated, where roles are flexible and problem-solving instead of blaming is the pattern for dealing with challenges, where families are able to ask for and receive assistance from others, and where beliefs and values are confronted and examined, the children and all family members are better able to manage their grief and support one another. Through establishing relationships with a child and family, nurses have the opportunity to bear witness to the family's functioning in both happy and difficult moments, which in turn provides important insight into supportive measures that would best honor their grief and bereavement.

Child and Siblings

Histories among siblings are closely intertwined because siblings often develop special bonds that are unlike any other. The closer two siblings are to one another before death, the more behavior problems the surviving sibling may have following the death.[37] Siblings may be forgotten as grievers; even teenagers may feel overlooked. Their needs can be ignored when a brother or sister dies—not for lack of parental concern, but because their parents are so overcome with grief that they have little energy for the needs of their surviving children. The impact of a child's death on surviving siblings is manifested in four general responses, best characterized in the words of the children themselves: "I hurt inside," "I don't understand," "I don't belong," and "I'm not enough."[37,39] Not all bereaved siblings experience all four responses, but most children through to adolescence demonstrate all responses to varying degrees.

"I Hurt Inside."

This first response includes all the emotions typically associated with grief—sadness, anger, frustration, loneliness, fear, guilt, restlessness, and a host of other emotions that characterize bereavement. Unlike adults, who are able to talk about their responses, children manifest their responses in various behaviors, such as withdrawing, seeking attention, acting out, arguing, fear of going to bed at night, overeating, or undereating. In response to children who are hurting inside, nurses need to allow, and even encourage, the expression of the hurt the children are feeling. Nurses can share their own thoughts and feelings with the children to let them know that they are not alone in this situation. If adults in the child's life do not allow for or facilitate expression of feelings, children learn that there is something wrong with such feelings and may suppress what is on their minds and in their hearts.

"I Don't Understand."

Children's difficulty in understanding death is greatly influenced by their level of cognitive development. However, once children know about death, their cognitive worlds are forever altered. Without guidance by adults in helping them to understand the death in clear, simple, and age-appropriate ways, children make up their own explanations, which usually involve taking responsibility for their sibling's death and their parents' distress. Without explanations, they can become more frightened and insecure. Nurses working with siblings should have a solid grasp of children's cognitive development, provide appropriate explanations for events that happen, and be open to supporting the family as questions from siblings arise.

"I Don't Belong."

A death in the family tears apart the usual day-to-day activities and patterns of living. Parents are overwhelmed with their grief, with making arrangements, and with caring for their other children. Surviving children are overwhelmed with the flurry of activity and the depth of emotion surrounding them. They often feel uncertain about what to do; they may want to help, but they don't know how, or, if they try, their efforts are often not acknowledged by grieving family members. Bereaved siblings may feel as if they are in the way or as if they are not a part of what is happening. They feel different from their peers as well and begin to feel that they don't belong anymore. Nurses play a critical role in encouraging parents to include siblings in illness- and care-related events, such as inviting the child to participate in certain treatments (for example, by holding their sibling's hand or blowing bubbles together for distraction during procedures). After death, the nurse can help the parents by modeling or guiding exploration of what to say to the surviving siblings.

"I'm Not Enough."

Assuming that they are somehow responsible for their parents' distress, surviving siblings may feel as if they are not enough to make their parents happy ever again. They may feel that their deceased brother or sister was the favorite child and that they should have been the ones to die instead. Some siblings respond by striving to be as good as they can be, trying to prove that they are worthy. Bereaved siblings benefit from feeling accepted just for being themselves and not from being compared with their deceased brother or sister. Moreover, surviving siblings may not want to burden their parents with their own feelings and may keep the depth of their grief private. Nurses can assist siblings to feel special by asking questions about their lives and acknowledging their unique characteristics or abilities.

Children and Adolescents at End of Life

Assessing and responding to a child's experience of serious illness is the very essence of palliative care provision.[40] Children experience their own disease progression and impending death within their cognitive and emotional capabilities, and they communicate such feelings to others as they are able.[41] They live and die as children, but often with much apparent wisdom, sometimes seeming to surpass that of their adult caregivers. In one of the earliest studies of seriously ill children, researchers found that very ill children are indeed aware of death and are more anxious than children hospitalized for nonserious illnesses or nonhospitalized children.[42] While remembering that there are individual variations within these patterns, this work provides nurses with background for understanding terminally ill children, such as this 14-year-old boy whose death is imminent:

> My mother used to go to church to pray for me early every morning. I also prayed in my bed for my mother to stop her soundless sorrow. We were all sad and we pray separately in different places. Now, I am getting more worried about how sad she will be after my death, and she will feel lonely without me. How can I express my sorrow for her and thank her? She has lost so many things . . . money, time, and smiles, all because of me . . .

Adolescents with a terminal disease struggle against physical pain, are sensitive to their parents' reactions, and have a strong desire to maintain relationships with their friends, regardless of their illness status: "I couldn't say anything with my Mom. She pretends to smile to me, but I know how she feels so sad whenever looking at me. I want to come out and share my emotions with my friends at least. But, now there is nobody around me."

Children and teens with terminal illness often wish to please their parents, and parents may want their child to maintain hope and not give up, resulting in barriers to honest communication.[43,44] In such cases, nurses are in a position to honor the feelings of all involved while helping family members to open to the possibility of truthfully sharing perspectives, hopes, and grief.

Child and the Healthcare Team

Professionals who care for children with serious illness are constantly reminded of the frailty and preciousness of life. When a child dies, healthcare professionals experience their own grief and also miss the relationship once shared through daily communication with the child and family.[45] *Caregiver suffering* is a contemporary term that includes moral distress and grief[46] and encompasses bearing witness to the suffering of another.[47–49] In one study of nurses' experiences following the death of a child,[50] participants described two types of distress: (1) *moral distress* resulted when the nurses knew the child's death was imminent and were required to carry out painful treatments they perceived as unnecessary, and (2) *grief distress* occurred in response to the child's death. Both types of distress resulted from lack of open communication within the care team and lack of consideration of the nurses' viewpoints.[50]

Working with children at end of life can also trigger nurses' awareness of their own personal losses and fears about their own death, the death of their own children, and mortality in general.

The process is complicated by cumulative loss—that is, a succession of losses experienced by nurses who work with patients with life-threatening illness and their families, often on a daily basis.[51] Nurses who work in settings where death occurs frequently seldom have time to grieve one child before the next death occurs on their unit.

Papadatou[52] described a framework for how professionals manage grief that entails fluctuating between both experiencing and avoiding intense emotions. An expert in the care of dying children, she notes that professional caregivers are profoundly affected by what is required of them in working with bereaved parents, other family members, and children and that they learn to regulate their grief.[52] For example, to manage the experience, a nurse may cry at a child's bedside and be fully present to a father who has just watched the removal of his child's ventilator. Later that day, the same nurse may avoid the intensity of the emotions garnered from the child's death to engage in a dinner out with her family.

Understanding the normalcy of the grief responses provides caregivers with an awareness of how they can simultaneously support families and themselves. Papadatou proposes that meanings are attributed to death and dying through grieving, that grief complications occur when there is no fluctuation, and that grief provides opportunities for personal growth.[52] Other researchers have found that caring for children at end of life provides opportunities for such growth and transformation, as healthcare professionals report finding meaning and enhanced life views through their work.[53,54]

Assessing Grief throughout the Trajectory of Care

Bereavement care is interdisciplinary in nature, with all team members collaborating to understand the experiences of each individual's grief, as well as those of the family as a whole.

Grief assessment begins when the child is diagnosed with serious illness and continues throughout disease progression, transition to end of life, death, and aftercare.

Five questions serve as a simple way for pediatric palliative teams to learn more about parents' perception of their child's needs and key issues:

- Who is your child as a person?
- What is your understanding of your child's illness (or condition today)?
- What are your hopes?
- What are your worries?
- What sustains you or gives you strength?[55,56]

These questions—followed by respectful probes such as, "What are the most important things we should address for you and your child right now?"[57] or "What do you think should happen next?[56]—can help to elicit what is weighing heaviest on parents' minds and also serve as a bridge to learning more about their feelings. In addition, statements such as, "This feels so difficult," or "Other parents/children have told me . . . it sounds like this is similar to you," can aid in acknowledging the experiences of another and open a way for eventual sharing of tender feelings.

During such interactions, nurses should also be mindful of periods of extended silence because there may be much that the child or parent is holding deep inside that cannot yet be spoken aloud.[41] Honoring silence in a compassionate manner offers the child or parent the opportunity to focus on these private thoughts or grief that may eventually be spoken aloud and shared with a trusted healthcare professional.[57]

Family Assessment

The nurse's role is to assess each family's way of functioning and to realize that some families are more challenging to assess and work with than others. For example, some families may not wish to share information in the presence of their children, others do not wish to discuss matters with any relatives in the room, while other families include everyone in most discussions. Thus, it is important for the nurse to gather information over time and to talk with more than one family member to appreciate the varied perspectives. As trusted relationships are established with the child and family, the nurse can assess family functioning with questions such as, "What have you done in the past when you had a difficult decision to make?[56] or "Help me to know how your family found their way through previous losses (or deaths)." Responses to such questions can help the nurse identify strategies that will honor and facilitate the family's grief work.

Factors Affecting the Grief Experience

In assessing grief, the palliative team should keep in mind the range of factors that affect the grief of family members while noting those factors that put individuals and families at risk for disenfranchised or complicated grief. The passage of time is not a useful consideration in assessing grief responses; instead, one should assess the degree of grief's intrusiveness into each individual's life and the extent to which family members can carry out their usual activities.

Where or when a child died, decision-making about the death, memories of sights and sounds, degree of medical intervention, and the cause of death are all subjects that families discuss while exploring their grief during bereavement. Ideally, the location (home or hospital) of a child's death is based on the family's specific needs and requests, but circumstances (insurance issues, nursing shortages, transportation issues) may preclude achieving this goal. Long-term outcomes for bereaved parents and siblings suggest an early pattern of differential adjustment in favor of home-care deaths.[58,59]

Decisions made at the end of life, such as withdrawal of life support, may have left parents second-guessing or wondering afterward about their choices. Lasting images or smells may be comforting or concerning to families, depending on their associations. In fact, pain or other distressing symptoms the child might have experienced provide powerful material for families to struggle with during their grief. A full code that ends with the child's death is very different from a death in which the child slips away from an unconscious state. Death following years of treatment is experienced very differently from a death that happens quickly.

When families are less functional, practitioners may want to explore their experiences and offer potential resources one at a time, with considerable attention paid to the possible disruption that would result from each suggestion. In more functional families, a list of possible options can be presented and considered all at once. Most families value the opportunity to tell their story. Thus, listening becomes a central aspect of assessing and caring for all grieving families.

Perinatal Considerations

Parents who experience perinatal death suffer deeply—yet, in the midst of suffering, there are moments in which human kindness and exemplary professional practice can make a difference. Perinatal palliative care allows professionals to demonstrate the deepest of human responses and to understand that the meaning of life is embodied by the very youngest in our world.[60] As the team and family "hope for the best while preparing for the worst,"[61] the act of therapeutic birth planning allows expectant parents the emotional space to discuss their needs with one another, express their grief, and plan for the anticipated death of their child.[7,62] Munson and Leuthner[63] outline a framework for perinatal palliative birth planning that includes engaging families in the exploration of their wishes, providing options, and allowing choice. Families vary in their ability to communicate effectively about their distressing thoughts and feelings. In order to make decisions collaboratively when planning for their baby's birth and death, they may need support from staff.[64] Perinatal palliative care teams can gently inquire about the meaning of the pregnancy and the baby's prognosis to help parents both acknowledge their feelings and discern those things that they find most important for their baby's care.[63]

Interventions and Supporting the Bereaved

Nurses, in particular, play a central role in a family's initial bereavement experience, holding in mind the family's sense of loss while pursuing with interdisciplinary team members care that best addresses the bereaved family's well-being. Most children's deaths still occur in the hospital; nurses are most often present at the time of death. If not with the child at the moment of death, the nurse is usually the first one called to the child's bedside. The nurse's words and actions at that time leave indelible imprints upon family members. This next section explores strategies for supporting bereaved individuals as they grieve the loss of a beloved baby or child.

Guided Participation

Pridham's *Guided Participation Theory* is an example of a teaching/learning relationship-based practice adapted for clinical intervention through approximately three decades of research by Karen Pridham and colleagues.[65,66] Table 63.3 shows the three components of guided participation: processes, competencies, and issues. The focus of guided participation is the caregiving of children, applied here for families and healthcare professionals caring for families in perinatal and pediatric palliative care settings.

Table 63.3 Framework of guided participation in perinatal and pediatric palliative care

Processes	**Competencies**	**Issues** (Examples of the many potential issues that arise in perinatal and pediatric palliative care)	**Notes on potential ways of guiding the parent**
Getting and staying connected	Being with	Parent expresses that he does not understand the MD's explanation of baby's condition	Process: **Structure the learning** by using drawings, brochures, explaining small pieces of information. Note whether **joint attention** is achieved by having parents describe what they have learned. Competency: **Communicating**
Joining and maintaining attention	Knowing and relating to the other as a person	Deciding how to tell others about a baby's prenatal diagnosis	Process: Create a **bridge** from this need to another: "How have you told someone distressing news before? How did it go? Is there anything you would do differently? Assess **shared understanding and transfer responsibility** by guiding the parent through practice time. Competency: **Problem solving/Decision-making; Communicating and engaging**
Sharing understanding	Communicating and engaging	Determining when a baby's suffering is a burden that outweighs potential life-saving interventions	Process: **Achieving joint attention and sharing understanding** with parents and healthcare team Competency: **Knowing and relating to the baby; problem solving and decision-making**
Bridging	Doing the task	Figuring out how to engage an uninterested health care professional in creating a perinatal and/or pediatric palliative care service	Process: Work toward **getting and staying connected (i.e., develop a relationship)** and move toward **joining and maintaining attention** Competency: **Knowing and relating; communicating and engaging; problem solving and decision-making**
Structuring the task/learning	Problem solving/ decision-making	How to assess whether a parent needs further intervention for potentially complicated grief	Process: **Structuring the task/learning** about symptoms, parent's emotions and cognitions; **Transferring responsibility** for mental health assessment as needed Competency: **Regulating emotion**
Transferring responsibility	Regulating emotion	Determining best practice for supporting a mother whose baby was diagnosed with anencephaly at 19 weeks gestation	Process: **Getting and staying connected; joining and maintaining attention; sharing understanding** Competency: **Being with the HCP and baby; knowing and relating to both as persons; sharing understanding**

Source: Adapted from Reference 66. Used with permission.

Caregiving theory, reciprocal to attachment, involves nurturing, protecting, and socializing a child. Researchers have found that caregiving is central when a diagnosis of a life-threatening condition in the fetus is made during pregnancy.[15] Mothers receiving perinatal hospice support expanded caregiving theory by talking poignantly in interviews about their long-lasting grief and bereavement and the importance of final acts of caregiving.[15] They provided a new understanding of the caregiving relationship with a child who may not have been seen and touched until after death. Examples of caregiving during pregnancy included speaking lovingly to the baby (nurturing), being cautious about diet and activity (protecting), and describing the baby by explaining his or her movements and showing an ultrasound photo (socializing).

Caregiving for a child from infancy through adolescence may include lying in bed with a child who is ill (nurturing), instructing family members and friends about health precautions when visiting a child whose immune system is compromised (protecting), or placing a child who lacks mobility in a wheelchair and taking her to the rooftop deck of the hospital to feel sunshine on her face (socializing). Acts of normal parental caregiving, such as reading a story, bathing the child, or bedtime hugs take on a new layer of meaning when shared within the context of EOL care.

To aid in understanding the key points of guided participation and its applicability to grieving families, several examples are included in Table 63.3. In addition, Figure 63.2 provides a visual depiction of guided participation, which can begin at any point (represented in the figure's triangular shape). For example, one may first identify an issue (e.g., the nurse assessing a family's preferences for being with their child who is dying), the need for a competency (e.g., the parent articulating EOL care choices that would be meaningful), or the focus for a process (e.g., joining attention).

Teaching and learning are often bounded by the idea that the expert provides information and the other learns by taking in the information, remembering it, and changing or enhancing behavior accordingly.[82] Such a definition is far too narrow. The most important component of guided participation is that it is based on the relationship between the teacher or guide (typically the one with more knowledge and experience) and the learner (the one who has a need for specific learning or information). In perinatal and palliative care situations, healthcare professionals should be mindful that they are not always the teacher because parents and the child are experts in their own values, goals, and expectations for the child's care.[67]

When using guided participation in palliative care situations, it is helpful to reflect, to take a step back, and mindfully examine all that is going on. This helps the guide to begin guided participation, which always has relationship as its center. Since guide and learner are both teachers and learners (participatory learning), it is common to use the process of getting and staying connected to begin. The process has as its goal fostering the competencies of being with and knowing and relating to the other (see Table 63.3). For example, when a young boy with terminal cancer shared quietly that his Lego superhero figure could "probably fly up all the way to heaven, too," his palliative nurse used this interest in his toy figures to establish rapport that eventually led to the boy disclosing how he would miss his family and toys when he died.

Salient features of relationship "are trust in sensitive responsiveness and respectful confidence in engagement in the process."[66] Gaining trust includes both mind and emotion. One child mental health specialist highlights the role of "being held in mind"[68]—that is, being thought about in one's absence—as a strongly motivating factor for the clinician in developing trust. This could be conveyed simply as, "I've thought about what you asked me yesterday before I left" or "I smiled this morning as I was getting ready for work, thinking of Jeremy's smile." Being in relationship may also mean sitting together quietly in the child's room, with both parents and the healthcare professional realizing that gaining trust and being with can also occur in moments of silence, especially at painful times when words are difficult to utter aloud.

Using guided participation in daily practice, specifically in the context of grief and bereavement, requires the guide to be alert to nonverbal cues such as looking away, silence, tears, or even being absent from the child's bedside. To understand how the parent defines the issue at hand requires observation and likely sensitive questioning. The guide is interested in what is on the parent's mind that led to the observed behavior. Being in relationship with the parent can lead to the nurse saying, "You seem a bit quieter than you did this morning. I'm wondering if you have identified

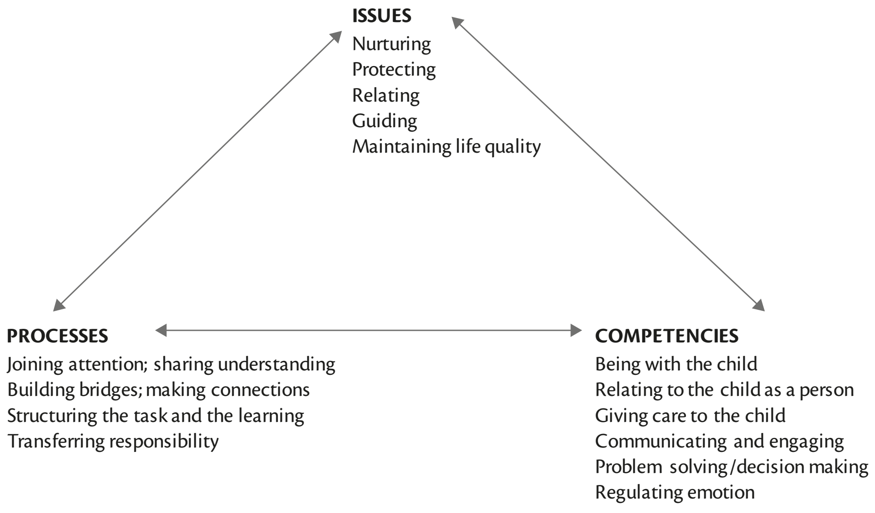
ISSUES
Nurturing
Protecting
Relating
Guiding
Maintaining life quality
PROCESSES
Joining attention; sharing understanding
Building bridges; making connections
Structuring the task and the learning
Transferring responsibility
COMPETENCIES
Being with the child
Relating to the child as a person
Giving care to the child
Communicating and engaging
Problem solving/decision making
Regulating emotion

Figure 63.2 Guided participation issues, processes, and competencies triangle.
Source: Reference 66, chapter 1. Used with permission.

something for your child or yourself that we should talk about." Another example could be an acknowledging invitation such as "It is important to me to know more about what you expect of yourself in relation to your children at home. Would you like to talk about that? I notice you are holding their photo."

The process of joining and maintaining attention, also referred to as "joint attention" requires that guide and learner understand whatever the issue is in a like manner—that is, that they share understanding.[66] Numerous potential issues could result in lack of shared understanding, such as navigating the complex needs that arise for the grieving family as a child's condition significantly deteriorates. In such moments, both the family and the child's team will experience a shift from familiar interactions to new, more uncertain situations.[67] The relationships that support a guided and participatory approach to teaching and learning can result in a shared understanding between family and team that results in choices, such as facilitating a beloved family pet's visit to a child's bedside at end of life or securing access to the hospital fitness center so a father can use a punching bag to physically work through intense feelings as he anticipates his daughter's impending death.

To summarize, guided participation depends on sustaining a relationship, and such relationships are strengthened through holding another in mind. Key issues for the child's care and the family's grief support can be addressed through establishing joint attention and creating shared understanding.

Being Present for the Bereaved Family

Healthcare professionals may fear saying the wrong thing to a family member, or they may worry about not knowing what to say in the midst of such profound sadness and grief. A compassionate presence can be conveyed through thoughtful words acknowledging a family's love for their child, by holding them in mind,[68] and by bearing witness to their experience. A nurse can sit or stand quietly, close to the family, let them know that they can stay with their child for as long as they would like, comment on the child's special qualities, and acknowledge his or her own sadness about the child's death. Offering to help in practical and concrete ways is also helpful.

Most family members have a need to share their story, telling and retelling anecdotes about the child and the events of his living and dying. Listening to their stories is probably the most helpful action. For some families, reviewing what happened with their child with the care providers is critical. Meert and colleagues' innovative parent–physician bereavement meetings provide parents the opportunity to review the events surrounding their child's dying and death in the pediatric intensive care unit.[69] Bereaved parents report that such meetings helped them to understand the biomedical reasons for the death and to review their decision-making, resulting in making sense, finding benefit, staying connected with their child, and reconstructing their parental identity.[69]

Follow-up telephone calls or visits with the team members who cared for the child are much appreciated by families. This is especially true for those parents who, over the many years of their child's care, developed close relationships with their child's team members. Such families worry that the team will forget their deceased child; some families want to maintain an ongoing connection with those who cared for their child.[70] Thus, during the transition after the child's death, families and staff must navigate the changing relationship.

Preparing Bereaved Parents for Their Grief Experience

Many parents who are unaware of the normal manifestations of grief can find some comfort in knowing that their experience is normal. Providing information about the common facts of grief can be helpful; having written materials to send home with families is even better. Understanding that each person's grief experience is unique helps parents understand that there is no single right way to grieve. It also helps them realize that they are not bad or crazy if they do not express their grief in the same ways that other family members do.

Team members should identify any need for additional assistance and make referrals as necessary. For example, a family member may have spiritual concerns that would be best addressed by the spiritual care provider (e.g., "We just cannot understand how this could happen to us"), or a social worker may assist with funeral arrangements or financial concerns (e.g., a father apologizes for not being at his child's bedside more, stating, "We just don't have the money for bus fare").

Parents, as individuals, may have different styles of grieving. Nurses can help by acknowledging the normality of a variety of grieving styles and encouraging parents to understand each other's ways of grieving. Differences in bereavement response also may lead to a strain on the couple's sexual intimacy. Again, pointing out that such reactions can be expected may help couples realize that their reactions are normal.

Supporting Bereaved Grandparents

Grandparents, like their adult children, benefit from compassionate bereavement support. Healthcare professionals should be especially attentive to those grandparents who were actively involved in their grandchild's daily care. In one study, researchers found that grandparents who provided childcare for their grandchild experienced more intense symptoms of grief, depression, and posttraumatic stress disorder than grandparents who were not directly involved in caregiving.[71] Grandparents report valuing the opportunity to participate in intergenerational perinatal bereavement programs, receiving support with the entire family following a perinatal death.[72]

Grandparents can also benefit from an individualized approach to bereavement support that takes into account and honors their life experiences. For example, in the R family, when Grandfather R was 10 years old, his older brother was killed in a car accident. At that time, no one explained what had happened, he was not allowed to attend the funeral, and, following the death, he regretted that he had not been the one to die because he felt his brother was so much smarter than he. As a young boy, he decided unconsciously that he would hide his pain behind a wall of silence; he seldom displayed or talked about emotions. When Grandfather R's grandson died from cancer at age 11 years, Mr. R was flooded with memories and sadness about his older brother's death. His previously learned coping through silence and withdrawal resulted in his being unprepared to help either himself or his distraught son with the current loss. A healthcare team sensitive to the entire family's grief could provide a healing balm for Mr. R's aching heart by encouraging him in a loving and compassionate way to share his story. One suggested way of opening conversation would be: "We've learned over the years that it is not uncommon for grandparents to have experienced past losses that are triggered by this one. Does that sound familiar to you?"

Grief Support for Children and Teens

Given the family focus that is central to perinatal and pediatric palliative care, healthcare professionals are also present to siblings whose brother or sister is seriously ill. Still, bereaved siblings may harbor lingering questions and concerns along with the normal manifestations of grief. Thus, siblings can be at risk for negative long-term outcomes of a brother's or sister's death. How adults and other providers respond to children's and adolescents' grief has the potential to intensify the risk of problem behaviors or, conversely, to promote healing and health. Adults' ability to optimally support grieving siblings depends in large part on their understanding of the typical or normal reactions that characterize siblings' grief and siblings' reactions as an attempt to make sense of a senseless situation and to act out their distress.

Grief is a human response. Children and adults alike feel denial, anger, sadness, guilt, and longing in response to the loss of a loved one. They may experience lack of sleep, lack of appetite, and difficulty concentrating and maintaining usual patterns of interaction with others. However, most children have limited ability to verbalize and describe their feelings; they also have limited capacity to tolerate the emotional pain generated by open recognition of their loss.[73] Moreover, children's cognitive developmental levels interfere with their ability to understand the irreversibility, universality, and inevitability of death and to understand the reactions of their parents. They also deeply fear being different in any way from their peers and, therefore, are often unable to find comfort, as adults do, in sharing their discomfort with their friends.

Play is the work and the language of childhood, so children are often able to express their feelings through their play, as well as through music and art. Bereaved children will benefit from spending time with art therapists, music therapists, or child life specialists who can foster creative avenues for children to process their experiences and grief. During an art therapy session with clay, a young girl carefully and quietly made a creation, then smashed it flat. After observing her repeat this action, the art therapist inquired what she was thinking about. Following more silence, the girl eventually confided that she heard when someone dies they get a new body, so she was trying to figure out what her new body would look like. This confession was the first time she expressed an understanding of her terminal condition and opened the door for honest communication among the child, her parents, and team.

Self-help support groups for teens, either in person or via the Internet, often prove valuable to grieving adolescents. Adolescents are often open to writing, art, or music. Adults may come along on such journeys or share the results, but they should take care to follow the adolescents' lead, respecting confidentiality and permitting them to interpret the significance of their grief work in their own way.

Bereavement Support Groups for Siblings

Peer support groups can often help siblings in ways their parents may not be able to because they are overwhelmed with their own grief.[74] Parallel support groups for parents can offer them support, as well. In the past nearly four decades, the number and types of peer support groups have grown considerably and are offered in nearly every state within the United States. In response to the ongoing development of such groups in the United States, the National Alliance of Grieving Children was formed in 2004, serving as an umbrella nonprofit organization to provide resources and education for the many children's bereavement programs and models.

The principles that underlie the Dougy Center's bereavement support program for children have been widely accepted and expanded by numerous other programs.[75]

- Grief is a natural, normal, and healthy human reaction to loss, so the goal of support groups is to normalize children's grief experiences.
- Within each child is the capacity to heal, but this does not happen within a vacuum. Their resilience is enhanced by such factors as strong social connections that are facilitated by having children meet individuals in similar situations.
- The duration and intensity of grief are unique for each child despite sharing broad developmental similarities with peers of similar ages. Programs do vary in structure and format (depending on the setting, resources, and intent), with some being time-limited and others ongoing, and with some being curriculum-based and others nondirective. This variety helps match children with the group most suitable for them.
- Caring and acceptance assist in the healing process. Thus, efforts are directed toward providing a safe, contained environment in which bereaved children can share their experiences and can ably chart their own course through grief, rather than simply accommodating the wishes of others.

Bereavement support groups provide children with opportunities to express their emotions, including the hurt, sadness, and pain associated with grief. Art supplies, musical instruments, outdoor and indoor play equipment, quiet corners, rituals—all serve this purpose. Being with others in similar circumstances, children can listen to and learn from them about their experiences with death and grief. From the adult leaders, siblings also can learn such things as the facts about various illnesses, treatments, or dying and death, thus helping to clarify any misunderstandings they might have.

Groups are not for everyone. Depending on their individual preference, preexisting mental health, behavior, or family system challenges, some grieving siblings and/or their families might benefit more from individual or family therapy. Thus, orientation sessions about support groups must be conducted prior to children joining a peer support group to assess the fit between each child and the program.[75,76]

Supporting Grieving Healthcare Professionals

Caring for dying children requires nurses to explore, experience, and express their personal feelings regarding death. Reflection is a key process for pediatric palliative care nurses in being with the child and family before, during, and after death.[77–79] The PRAM model incorporates reflection and self-awareness as one *P*auses, *R*eflects on what is happening, *A*cknowledges one's feelings and thoughts, and is *M*indful when starting a new encounter with others.[2] When using the PRAM while working in perinatal or palliative care settings, the nurse may consider these questions:

- What is happening in my personal life right now that may affect my interactions with this child and family?
- What personal thoughts, feelings, values, or biases come to mind as I engage with this family?

- What expectations do I have for the care of this child and the child's family?
- What have I learned from team members that I should either hold in mind or place aside as I enter into relationship with the family?
- How does this family remind me of past experiences with other children? What did I learn from them that I might carry with me or lay aside at this time?[74]

Self-awareness about one's own history of loss and one's own beliefs about death, dying, and the afterlife is essential to ensure that our personal preferences do not interfere with the experience of the family. Personal death-awareness activities and exercises, discussion of belief systems about death/afterlife with friends and colleagues, self-exploration, and reflection may promote an understanding and acceptance of death as part of life. After significant interactions and patient death, a nurse can also engage in self-awareness by honest reflection through these questions:

- What affected me the most from this case?
- What went well?
- What surprised me?
- What hurt the most?
- What do I wish I could have done differently?
- What did I learn from this child that I will carry with me to my next patient?

Nurses have responsibilities for acknowledging their own personal and professional limitations, seeking assistance, and engaging in self-care activities. They must give themselves permission, space, and time to process feelings when a beloved patient dies and to regulate when and how to become connected in relationship again with the next child and family. Free-writing, journaling, poetry, music, art, ritual—all have a place in processing professional experiences of grief.[79–81]

When the death of a child resonates throughout the child's entire team, opportunities for group reflection can be helpful to process the impact of the loss together, especially if the death occurred unexpectedly or was traumatic to the team.[82] In such situations, facilitation of team processing should be offered using differing strategies over time to meet the unique needs of each grieving healthcare professional.[82–84]

Hospital Bereavement Programs

Development of interdisciplinary perinatal and pediatric bereavement programs in healthcare institutions has increased notably in the past decade despite budget and resource concerns.[85–89] A bereavement program within a pediatric palliative care program, or as part of an agency or system-wide initiative, can be of considerable service to both families and staff. These services typically include staff with specific training in bereavement care and a follow-up component.[7] An interdisciplinary bereavement team ensures that all families are educated on and supported in their grief and are made aware of available services, such as support groups, memorial services, or grief workshops. Bereavement program leaders facilitate family referral to grief therapists as needed and may also help bereaved families to be with one another as a source of support. Parents report feeling supported by staff through hospital bereavement programs and value the opportunities offered by such programs to grieve and stay connected with their deceased child.[86–92]

The existence of a bereavement program gives a clear message that an institution and its staff are committed to the care of families. In 2015, Advocate Healthcare, the largest health system in Illinois, formed a perinatal and pediatric bereavement council with interdisciplinary representatives from the system's 12 hospitals, with the goal of standardizing bereavement support care across all sites. This system-wide initiative has been successful in streamlining bereavement care processes, ensuring equity of resources across sites, and promoting high-quality, compassionate care for all families experiencing the death of a baby or child. Key initiatives to date have included organizing events for both families and staff and raising awareness of the needs of the bereaved.

In addition to helping bereaved families, institutional bereavement programs also serve the needs of staff. Programs can be structured to offer help in debriefing after a death, validating staff feelings, offering support groups, and encouraging informal support through the one-on-one sharing of experiences with coworkers, peers, or pastoral care workers.[82–85]

Ritual and Meaning-Making

Ritual is used by people across all time and cultures to mark or acknowledge significant life events,[90] providing opportunities for meaning-making and transformation.[2,91, 92]

According to Limbo and Kobler,[2] ritual creates a bridge from suffering to hope and reminds all involved of the importance of moments in the care of bereaved families. Ritual can also play an important role in helping healthcare professionals process their experiences and reconnect to the purpose in their work.[82,91]

Nurses can aid in co-creating ritual with both families and interdisciplinary team members. Discussions about ritual often begin when a nurse notices a parent letting out a deep sigh or sharing a poignant memory. In such moments, a nurse can inquire, "What is most important to you right now?" or "Holding in mind what you are thinking and feeling right now, what would be meaningful to do next?"[93] Answers can provide insight into ways that a ritual could honor all that is unfolding. For a mother whose baby was dying in the neonatal ICU, the idea of holding her baby over her heart was very important. Together, the mother and nurse decided to pause in silence, with the nurse letting the mother decide when and how to lift up and snuggle her baby close. The mother later shared how important it was to decide when and how she was ready for the ritual; for the nurse, this moment became a treasured reminder of trusting parents as experts in their children's care and in discerning their own grief support needs.

Children are intuitively drawn to ritual and are adept at co-creating ritual when invited to participate.[2] One young boy, standing at his sister's gravesite burial ceremony, noticed all of the flowers nearby. When the chaplain finished speaking, the boy asked aloud what would become of the flowers. The chaplain wisely asked the little boy to share more what he was thinking about, which led the boy to declare that he wanted to give his sister one last flower. With his parents' tearful permission, the boy carefully took out a single white rose from a nearby arrangement, knelt down before the open grave, and reverently tossed the flower in. Without spoken word, his parents followed their son's action, and eventually all present chose a flower and knelt to honor the boy's sister one last time . . . a ritual that arose out of the moment and connected all participants together in a meaningful way.

Box 63.1 Resources

Membership Organizations

- *Pregnancy Loss and Infant Death Alliance (PLIDA)* (www.plida.org).

As the only perinatal bereavement member organization, PLIDA offers numerous evidence-based position statements, a biennial 3.5-day conference, member online forum, and best-practice research. The organization includes healthcare professionals and parent advocates.

- *Hospice and Palliative Nurses Association* (HPNA) (http://hpna.advancingexpertcare.org/).

HPNA offers education, a research scholars program, numerous opportunities for certification (e.g., perinatal bereavement and pediatric palliative care), and publications.

- The *National Association of Neonatal Nurses* (NANN) (www.nann.org)

NANN is a membership organization including a community of registered nursing professionals who care for infants born with a variety of health challenges and surgical problems.

Education (Writings, Websites, and Conferences)

- *Children's Project on Palliative/Hospice Services* (ChiPPs) newsletter, published by the National Hospice and Palliative Care Organization (NHPCO) (https://www.nhpco.org/chipps-e-journal). The November 2017 issue was on perinatal and pediatric palliative care. Visit the website to sign up for the newsletter, published quarterly.
- *PerinatalHospice.org* (http://www.perinatalhospice.org/) is a clearinghouse of information about perinatal hospice and palliative care, including many resources for parents and caregivers as well as an international list of programs.
- *Blueprint for a Perinatal Palliative Care Program Toolkit*. Available from Resolve Through Sharing at https://glbereavement.dcopy.net/product/rts-2025-perinatal-palliative-program-tool-kit. The kit is divided into four sections: (1) organizing your work, (2) communication and documentation, (3) educational resources for parents, and (4) educational resources for staff. The kit includes handouts, sample forms, algorithms, and more.
- *Palliative and End-of-Life Care for Newborns and Infants Position Statement #3063* (2015). Drafted by Anita Catlin, DNSc, FNP, FAAN; Debra Brandon, PhD, RN, CCNS, FAAN; Charlotte Wool, PhD, RN; and Joana Mendes, PhD, RN. Reviewed by Brenda Barnum, MA, RN. Approved by the NANN Board of Directors. Downloadable from the National Association of Neonatal Nurses (www.nann.org).
- Limbo R, Toce S, Peck T. *Resolve Through Sharing (RTS) position paper on perinatal palliative care* (Rev. Ed.). La Crosse, WI: Gundersen Lutheran Medical Foundation, Inc.; 2008–2016. Downloadable from www.resolvethroughsharing.org.
- Wilke J. *Investing in Resolve Through Sharing Creates a Culture of Compassion, Enhances Quality, Improves Patient and Staff Experience, and Supports National Standard Benchmarks.* La Crosse, WI: Gundersen Lutheran Medical Foundation, Inc.; 2014. This white paper includes industry standards and where you can find them; the latest research on caring for someone after perinatal, pediatric, and adult death; public education that emphasizes conversations within families focused on the elements of advance care planning (e.g., medical facts, goals, values, and beliefs); timely facts on Accountable Care Organization (ACO) and Electronic Healthcare Records (EHRs); and perinatal loss certification.
- Resolve Through Sharing (www.ResolveThroughSharing.org) is a provider of interprofessional bereavement education since 1981, including training in perinatal death (including perinatal palliative care) and training in neonatal/pediatric death (including pediatric palliative care). Training for those who want additional program implementation, leadership, and education skills is offered through Resolve Through Sharing Coordinator training (offered since 1985).
- *End-of-Life Nursing Education Consortium* (ELNEC) has provided nursing education since 2000. Courses include a core course, pediatric palliative care, and, new in 2018, ELNEC Communication, in addition to numerous other offerings. For more information, visit http://www.aacnnursing.org/ELNEC.

Certification

- Certification in perinatal bereavement (Certified in Perinatal Loss Care) and as a pediatric nurse (Certified Hospice and Pediatric Palliative Nurse) is available through the *Hospice and Palliative Credentialing Center* (http://hpna.advancingexpertcare.org/).

Specialized Bereavement Products for Family Support When an Infant or Young Child Dies

- Memory boxes, the presentation and handling system (Preshand System), and the Keepsake Impressions Kit for infants and toddlers are unique products designed by the team at Memories Unlimited. Available at http://www.gundersenhealth.org/resolve-through-sharing/shop-our-products/ (for purple products) or call Memories Unlimited at 360-491-9819.

Conclusion

Healthcare professionals bear witness to the impact of a child's serious illness and death on all who love and care for the child. Providing compassionate bereavement care when a baby or child dies begins with honoring the relationship and requires a willingness to be present, to listen carefully, and to offer individualized strategies to support those who grieve. Through the children and their families, healthcare professionals are reminded of the fragility of life and that hope and love are everlasting. See Box 63.1 for additional resources.

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CHAPTER 64

Pediatric Pain

Knowing the Child Before You

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Key Points

- Infants and children experience pain.
- Pediatric pain assessment is specific to age and developmental level and includes both observational and self-reporting tools and strategies.
- Pain management plans are individualized based on the pain source and physiology (acute vs. chronic, somatic vs. neuropathic), the patient's history (past pain experience), and the patient's goals for pain management.
- Children and their families should be engaged in assessment and management of pain.
- Pediatric medication dosing is based on the child's age and body weight, and potentially on hepatic or renal function.

Introduction

Children and infants, like adults, experience pain as a serious complication of disease and injury. Unfortunately for this vulnerable patient population, it is only recently that clinicians have come to understand that children experience pain, due to a surge in publications on neonatal and pediatric pain in the 1980s.[1] Previously, it was thought that infants were unable to perceive pain due to early neurodevelopment. Exposure to painful injury is associated with psychological consequences in children, including posttraumatic stress symptoms.[2] Pain exposure in infancy impacts future neurodevelopment of babies and is associated with increased anxiety and cortical dysfunction in childhood.[3] In seriously ill infants, pain may be associated with increased morbidity and mortality.[4] In older children, untreated pain can lead to decreased functioning, social isolation, sleep disorders, and mood changes. Children may have exaggerated future responses to painful or nonpainful stimuli based on past painful experiences. Prevention and relief of pain for this vulnerable population can help them to grow as children.

Pain assessment and management in infants and children require that palliative care nurses understand the developmental stages of childhood. A child's response to pain may differ based on his or her developmental stage. Careful attention should be paid to eliciting the child's and family's perspectives about pain, including past pain experiences, cultural and social perspectives on pain, and individual behaviors around pain. Children and families should be engaged as a part of the healthcare team, with their input being important in the management of pain. The pediatric pain experience can be influenced by emotional, psychological, and existential distress, just as in adults.

Pediatric Pain Assessment

Taking a Pain History and Self-Reporting Pain Scales

Self-report of pain is an integral part of the pediatric pain assessment whenever it is developmentally and clinically feasible. At the same time, self-report is not the only aspect of the pain assessment; it is considered along with behavioral observations, parental report, and clinical data.[5]

Children can affirm or deny pain at a young age. The ability to describe pain will correlate with the child's expressive language and vocabulary. The interviewer should be mindful to use a word for pain that the child is familiar with such as "hurt," "owie," or "ouchie." Toddlers can begin to communicate pain location either with words or by pointing but may not always be consistent or reliable. A preschool-aged child (>3 years) begins to be more reliable and can utilize a self-reporting pain scale such as the Faces Pain Scale – Revised: six cartoon faces that depict varying levels of pain severity. The child is asked to "point to the face that shows how much you hurt right now."[6] A school-aged child (>8 years old) may be able to provide a more detailed pain history, and the interviewer can use similar questions to those utilized in obtaining a pain history from an adult (Box 64.1). School-aged children with numerical processing skills (about age 8) can make use of the Numeric Rating Scale. See Table 64.1 for examples of pediatric self-reporting pain scales. If a child's self-report when using a validated scale does not correlate with the clinical observation and/or pain behaviors exhibited, the nurse should clarify the child's understanding of the pain scale and potentially utilize a different scale. This is an opportunity for "teach back," having the child explain the pain scale to the nurse. It is important for the interviewer to be mindful of the motivations to underreport or overreport pain (see Table 64.2 for examples). The nurse could also use reflective listening to clarify his or her understanding of the child's report, "I hear you say that you are not having any pain, but then again you are not wanting to get out of bed or move around. What do you feel in your body?"

Box 64.1 OLDCARTS Mnemonic for Obtaining Pain History

O: Onset: When and/or how did your pain start? Did it happen all of a sudden?

L: Location: Where is your pain? Can you point to where you hurt on the stuffed animal?

D: Duration: How long does your pain last? All day vs. comes-and-goes?

C: Characteristics: How would you describe your pain? What does it feel like?

A: Aggravating factors: What makes your pain worse? What makes it hurt more?

R: Relieving factors: What makes your pain better? What takes the "ouch" away?

T: Treatments: What treatments have you tried to help make it better? Play, movement, being held by parent?

S: Severity: Rate your pain using a given pain scale. How much is your pain affecting your life (mood, sleep, daily functioning)? Can you play/sleep/eat/move with the pain?

Physical Exam and Observational Assessment of Pain Intensity

For children who cannot self-report either due to age (infants and toddlers), developmental disability, or medical intervention (i.e., intubation), the caregiver must rely on observational signs of pain and parent/caregiver report. Examples of age-appropriate observational pain scales are listed in Table 64.3 [7–9] For those children who can self-report pain, it is still important for the examiner to also observe the child's behavior for signs of pain as part of his or her physical exam. Examples are listed in Table 64.4. The nurse should note congruence between the self-report of pain and presence of pain behaviors. If there is a positive self-report of pain *and* pain behaviors are observed, this congruence supports the child's pain experience. Incongruence between self-report and behavior does not invalidate the pain report; for example, a child may report no pain on the numeric scale but have limits to function and grimacing during activities of daily living. The examiner should first ensure that the child understands the self-reporting pain scale to avoid misinterpretation and then, once again, be mindful of motivations to underreport pain. Conversely, children who suffer from chronic pain, such as with rheumatoid arthritis, sickle cell disease, or chronic pancreatitis, may report a significant amount of pain but may not exhibit pain behaviors. For these children, assessment of daily functioning may better indicate their level of impairment from pain.

Just as in adults, some children can articulate what is an acceptable or tolerable level of pain and what are acceptable or intolerable side effects from pain treatments. When children decline pain treatment, caregivers and clinicians should seek to better understand the child's reasoning. Children may misunderstand the purpose, effects, or risks of the treatment or medication. If children do not like the taste or side effects of a given treatment, other therapies or medications can be trialed. Children and adolescents may prefer to tolerate pain as opposed to feeling lethargic or impaired from pain medications. This can become distressing for caregivers and clinicians caring for children and adolescents, particularly for those at the end of life. Care should be respectful and honor the wishes and values of the child or adolescent with respect to pain management. Consider further assessment of cultural or religious beliefs around the experience or presence of pain.

Case Study: A Pediatric Patient with Pain

Brian was an 8-year-old boy with end-stage metastatic rhabdomyosarcoma who was receiving oral palliative chemotherapy. He reported generalized body pain (3–5 out of 10 on numeric scale, sore with deep aching feeling) and described it as tolerable (reports that tolerable is up to 6/10 on numeric scale). He was using heat packs, gentle massage, and distraction with movies, as well as scheduled acetaminophen and ibuprofen for pain management. Brian described "the worst pain imaginable" was after he had a thoracotomy to resect pulmonary lesions, which was several months ago. On your assessment, Brian was observed to be cachectic and weak, moving gingerly and wincing when turning over in bed, he preferred to be carried in and out of clinic by his dad as opposed to using a wheelchair. The oncology team wanted to trial long-acting opioids in the hopes of improving his pain control, but Brian refused, stating he didn't like the way opioids "made him feel in his head," that they made him sleepy and not himself. Brian had trialed oral oxycodone, oral morphine, oral hydromorphone, and methadone, each one with a similar intolerable side-effect profile. While oncology and palliative care teams continued to work with Brian and his family to find alternative methods of improving pain control, they respected Brian's desire to avoid sleepiness to maximize time awake with family and friends. Brian was discharged to home with recommendations for continued use of nonpharmacologic and nonopioid therapies, as well as a prescription for an as-needed oral opioid should pain progress to more than tolerable.

Table 64.1 Pediatric self-reporting pain scales

Age	Scale	Parameters	Comments
4–12 years old	Faces Pain Scale – Revised	Uses six cartoon faces showing increasing signs of pain/distress	Complete instructions and translations may be downloaded at www.iasp-pain.org/FPS-R
>8 years old	Numeric Rating Scale (NRS)	Uses a 0–10 scale where 0 denotes no pain and 10 signifies the worst pain. *Hint*: It is helpful to note what the child considers to be "the worst pain imaginable." The "anchor effect" may lead to misinterpretation or skewed pain report (e.g., whether a "10" to an individual child is a stubbed toe vs. multiple broken bones)	Requires language skills and numerical processing To reduce failure rates, consider use of a visual analogue scale (a 10 cm visual scale) or Faces Pain Scale – Revised in children 8–12 years of age who do not seem to understand the NRS

Table 64.2 Children's motivations for underreporting and overreporting of pain

Underreporting	Overreporting
Fear of being admitted to the hospital or having to stay in the hospital longer Desire for healthcare provider to leave the room Fear of needles or procedures that might come if pain is reported Fear of what admitting pain means (cancer returning, disease progression, becoming sicker) Social construct (boys/big kids don't cry) Lacking language to articulate pain Feelings that providers do not believe reports of pain	School avoidance Not wanting to be discharged from hospital Liking the way pain medicine makes one feel Getting more attention from parent/caregiver Not wanting parent/caregiver to leave bedside Fear of future pain

Assessment of Pain in Child with Severe Neurologic Impairment

Children with severe neurologic impairment who are nonverbal are at risk for the underrecognition and undertreatment of pain.[10] A child may be severely neurologically impaired from an anoxic or traumatic brain injury or from a specific disease, such as a congenital anomaly, brain malformation, or metabolic disorder. The revised FLACC is a pain scale to aid in the assessment of the nonverbal, neurologically impaired child.[9–10] When pain behaviors are observed, common sources of acute pain in the severely neurologically impaired child such as spasticity, dental caries, constipation, fracture, subluxation, and urinary retention should be considered and addressed.[10] If pain behaviors persist without any findings of tissue injury or inflammation indicating an acute pain source, then some experts propose that it may be reasonable to trial neuropathic pain agents, arguing for the empiric treatment of a central neuropathic pain syndrome in this population.[10]

Procedural Pain Management

Procedural pain is the most commonly experienced pain event of hospitalized children.[11] Hospitalized children experience painful procedures including venipuncture, intramuscular injections, lumbar puncture, heel lancet, subcutaneous port access, urinary catheterization, feeding tube placement, wound dressing change, and chest tube placement. Children who experience unrelieved or severe pain from procedures may in the future have a worse pain response to the same procedure or be avoidant of medical care altogether.[12]

In infants, procedural pain management includes caregiver education and preparation for the procedure (anticipated duration, steps prior to painful part of intervention, how to position infant, anticipated infant response), skin-to-skin contact with caregiver in position of comfort, and preemptive analgesia with sucrose and non-nutritive sucking or breastfeeding.[13]

In children, developmentally appropriate procedural preparation is important to help reduce pain perception. This includes counseling parents or caregivers on how to respond to their child in pain and how to support their child's positioning and coping during the procedure. Children should be offered guidance on what to expect from the procedure, with attention to how the child will be supported and what role the child will have in the procedure (i.e., counting, taking deep breaths, holding caregiver's hand, staying still). Children may benefit from medical play prior to the procedure to destigmatize the tools and environment (i.e., water play with needleless syringes, tour of casting room or lab draw station prior to procedure time). Child life specialists may be helpful in supporting the child's coping in a developmentally appropriate manner.

Children should be allowed to help with determining their positioning for the procedure in a way that supports comfort and safety. For toddlers, a hug position with arms and legs wrapped around parents may allow one arm free for intramuscular injection or phlebotomy procedure. School-aged children may prefer to sit on a parent's lap or in a chair facing away from the affected body part. For procedures around the eyes or face, children may prefer their head supported by a caregiver. Children should be allowed to hold a support object (stuffed animal or blanket) if desired and safe. When possible, avoid painful procedures in the child's hospital bed to allow this to be a safe space. Procedure rooms or sitting outside of the bed are alternative settings.

Children may benefit from visual stimulus such as pictures or moving lights. Distraction techniques include video games, having children identify objects in a book, singing a song, or listening to music. Hypnosis techniques may also reduce children's perception of pain.[14] Application of cold and vibration stimulus has also been shown to reduce pain during intravenous line starts.[15]

Preemptive analgesia is appropriate for procedures when pain is expected. This may include topical analgesia (lidocaine-based creams EMLA, LMX-4) or a needleless injection of lidocaine (J-Tip). Pharmacologic therapies are similar to those used in acute pain management, noting that onset and duration of action are

Table 64.3 Observational pain scales for infants, toddlers, and children

Age	Scale	Parameters	Comments
Infants (0–6 months)	CRIES	Assess *C*rying, *R*equired oxygen, *I*ncreased vital signs, *E*xpression (facial) and *S*leepiness. A score of 0–2 is given for each parameter based on changes in the patient's baseline	Score out of 10
Infants and Toddlers	FLACC	Assesses *F*ace, *L*egs, *A*ctivity, *C*rying, and *C*onsolability	Score out of 10
Developmentally Delayed/ Cognitively Impaired	Revised –FLACC	Uses same parameters as FLACC but allows for the addition of individualized pain behaviors	Score out of 10 Engage caregivers to help individualize this scale

Table 64.4 Observed pain behaviors

Age	Pain behaviors
Infant (0–12 months)	High-pitch crying Facial grimacing Furrowed eyebrows Difficulty sucking Frequent hiccupping Frequent yawning Avoidance of eye contact or inability to console Change in level of activity Irritability/Restlessness
Toddlers (12 months–4 years)	Facial grimacing Furrowed eyebrows Sleep difficulties Guarding area of discomfort Crying/moaning Decreased interest in play Irritability/restlessness Loss of appetite Needs to be held more than normal
School-aged and Adolescent (5–17 years)	Facial grimace Furrowed eyebrows Difficulty sleeping Crying Guarding area of discomfort Decreased activity level Withdrawn Irritability Anger Change in eating habits Breath holding

important to match with the expected duration of the procedure and resulting pain.

Acute Pain

Acute pain typically lasts less than 30 days and is associated with tissue injury, with improvement of pain as the tissue heals. Pain persisting more than 3 months and after the complete healing of tissue damage is then considered chronic pain. Examples of acute pain include postoperative pain, chemotherapy-induced mucositis pain, and sickle cell vaso-occlusive pain crisis.

Acute pain management includes nonpharmacologic and pharmacologic approaches. Medications should be used in addition to nonpharmacologic interventions—not instead of them. See Table 64.5 for examples of age-appropriate nonpharmacologic interventions for pain management. Updated in 2012, the World Health Organization (WHO) guidelines provide clinicians the basic tenets for the use of analgesics for pediatric pain management[16]:

1. Use a two-step strategy for pain medications, also referred to as "by the ladder."
2. Dose medications at regular intervals: "by the clock."
3. Use the least invasive route of administration: "by the mouth."
4. Adapt the treatment to the individual child: "by the individual."

Table 64.5 Nonpharmacologic interventions for pain management

Age	Nonpharmacologic interventions
Infant (0–12 months)	Cuddle/swaddle infant Skin-to-skin care Massage Dim lights Lower voices/noise Non-nutritive sucking (pacifier, bottle) Music Breastfeeding Physical therapy
Toddlers (12 months–4 years)	Positioning for comfort and control Distraction (storytelling, reading favorite book, games, play with toys) Art and music therapy Massage Guided imagery/visualization Physical therapy Relaxation through deep breathing (using bubbles or pinwheel) Heat or cold therapy
School-aged and Adolescent (5–17 years)	Positioning for comfort and control Environmental changes to promote safety Dim lights Procedural preparation Relaxation through deep breathing Guided imagery/visualization Distraction (television, reading a book, video games, board games) Art and music therapy Acupuncture (>8 years) Massage Hypnosis Aromatherapy Heat or cold therapy Physical therapy Biofeedback

Using a Two-Step Strategy

The pediatric two-step strategy replaces the three-step analgesic ladder introduced by the WHO in 1986. Like the three-step ladder, the two-step strategy outlines medications to be used based on the child's pain severity, but no longer recommends the use of weak opioids (e.g., codeine) for moderate pain. For mild pain, Step 1 treatments are nonopioids including acetaminophen and/or ibuprofen (or an alternative nonsteroidal anti-inflammatory); see Table 64.6 for Step 1 medications and dose recommendations. If the child has moderate to severe acute pain related to tissue injury, then Step 2 treatments are strong opioids, and these should be used in conjunction with Step 1 treatments. See Table 64.7 for Step 2 medications and dose recommendations.

Table 64.6 Treatment of acute pain Step 1: Mild pain, nonopioids

Medication	Route	Term neonate–6 months	6 months–12 years	>12 years	Maximum daily dose	Comments
Acetaminophen	PO, IV, PR	10–15 mg/kg/dose q4–6h	10–15 mg/kg/dose q4–6h	650–1,000 mg q4–6h	75 mg/kg/day or 3,000 mg	Avoid use in hepatic impairment; requires dose adjustment in renal impairment
Ibuprofen	PO		5–10 mg/kg/dose q6–8h	400–800 mg q6–8h	40 mg/kg/day or 2,400 mg/day, whichever is less	Chronic use increases risk of thrombotic events, gastrointestinal (GI) bleed, and renal impairment; may impair platelet aggregation
Naproxen	PO		5–7 mg/kg/dose q8–12h	250 to 375 mg q12h	1,000 mg/day	Chronic use increases risk of cardiovascular thrombotic events, GI bleed, and renal impairment
Ketorolac	IV		0.5 mg/kg q6–8h	15–30 mg q6h	120 mg/day	Increases risk of bleeding, stroke, GI bleed, cardiovascular events, and renal impairment Maximum duration of use 5 days
Celecoxib	PO		10–25 kg: 50 mg q12h	100–200 mg/day	400 mg/day may be used short term	Chronic use increases risk of cardiovascular thrombotic events, GI bleed, and renal impairment

Table 64.7 Treatment of acute pain Step 2: Moderate to severe pain, opioids

Medication	Route	Pediatric starting dose	Adult starting dose	Comments
Fentanyl	IV	0.5–2 mcg/kg IV bolus every 5 minutes–1 hour, 0.5–3 mcg/kg/hr continuous infusion	25–50 mcg/dose IV bolus every 5 minutes–1 hour, 25–200 mcg/hr continuous infusion	Skeletal muscle and chest-wall rigidity can be seen with rapid intravenous dosing Has no active metabolites and is considered relatively safe to use in patients with renal failure
	Intranasal	1.5 mcg/kg once (maximum: 100 mcg/dose); may repeat 0.5 mcg/kg every 5 minutes to a max of 3 mcg/kg given	100 mcg/dose	Use IV preparation
	Transdermal patch			Not intended for opioid–naive patients Half-life 20–27 hours, steady state reached after 2 sequential 72–hour patch applications Refer to Duragesic patch package insert for dose recommendations when converting from another opioid to a fentanyl patch
	Transmucosal (i.e., sublingual, buccal)	Not approved for use in children, could consider for adolescents receiving end-of-life care	100–200 mcg	Available as a lozenge, dissolving tablet, buccal film, sublingual spray Onset of action 5–15 minutes
Hydromorphone	Oral	0.03–0.08 mg/kg/dose q3-4h as needed	1–4 mg/dose q3-4h as needed	Use with caution in renal impairment (inactive metabolite accumulation can lead to neurotoxicity)
	IV	0.01 mg/kg/dose q3-6h as needed Continuous IV infusion: 0.003 to 0.005 mg/kg/hour	0.2 to 1 mg q2-3h as needed	

(*continued*)

Table 64.7 Continued

Medication	Route	Pediatric starting dose	Adult starting dose	Comments
Methadone	Oral	0.1 mg/kg/dose q4h for 2–3 doses, then q6-12h	Initial 5–10 mg; dosing interval may range from 4–12 hours during initial therapy; decrease in dose or frequency may be required (~2–5 days after initiation of therapy or dosage increase) due to accumulation with repeated doses	Not recommended for opioid naive patients Long and unpredictable half-life of 5–100 hours Used in management of opioid dependence and weaning
	IV	0.1 mg/kg/dose q4h for 2–3 doses, then q6-12h as needed; maximum dose: 10 mg/dose	2.5–10 mg q8-12h; titrate slowly to effect	Helpful in treatment of neuropathic pain given its NMDA receptor activity and has some inhibitory effect on the reuptake of serotonin and norepinephrine Use with caution in hepatic impairment, metabolized primarily by liver QTc prolonging drug, consider checking EKG prior to initiation and with dose titration
Morphine	Oral	0.2–0.5 mg/kg/dose q3-4h as needed	5–15 mg q4h as needed	Use with caution in renal impairment (inactive metabolite accumulation can lead to neurotoxicity)
	IV	0.05–0.2 mg/kg/dose q2-4h as needed continuous infusion: 0.01–0.04 mg/kg/hr	2–5 mg q2-4h as needed continuous infusion: 1 mg/hr	
Oxycodone	Oral	0.1–0.2 mg/kg/dose q4-6h as needed	5–15 mg/dose q4-6h as needed	

Opioids with Limited or No Use in Pediatrics

Medications that have limited uses in pediatrics include nalbuphine (Nubain), a mixed opioid agonist-antagonist. Nalbuphine can be helpful for an opioid-naive, postoperative patient whose acute pain is expected to get better quickly or to treat opioid-induced itching. Nalbuphine is not recommended for patients with pain that is expected to get worse before getting better (if it is expected to get better at all); in this case, a strong opioid is recommended.

Combined opioid and acetaminophen products should only be used with caution in children given the risk of dosing errors with both opioid and acetaminophen contents[17] and risk of hepatotoxicity with acetaminophen overdose. In pediatrics, it is preferred that the medication components be dosed and administered separately, even in acute surgical pain. For some children, surgical pain may be well-controlled with acetaminophen taken together with a nonsteroidal anti-inflammatory drug (NSAID). Others may benefit from having an opioid available as a separate third-line agent for breakthrough pain. This depends on the anticipated pain severity and recovery time. For children with disease-related pain that is expected to worsen over time, fixed opioid and acetaminophen combination products limit the flexibility for opioid titration at home since the dose is limited by the recommended daily acetaminophen maximum. If the opioid and acetaminophen are separated, the patient can take the same opioid scheduled around the clock and as needed for breakthrough pain.

The US Food and Drug Administration recommends against the use of codeine and tramadol in children and adolescents given the risk of oversedation with associated respiratory depression and potential death.[18] Both codeine and tramadol are prodrugs and must be metabolized by the body into their active metabolite to produce analgesia. There is genetic variability in metabolism: those persons who are ultra-rapid metabolizers will have too much of the active metabolite in their body too quickly and potentially suffer the side effects of opioid-induced respiratory depression.

Dosing at Regular Intervals

When pain is constantly present, analgesics should be administered at regular intervals, not simply on an as-needed (PRN) basis. With as-needed dosing, the risk is undertreatment and uncontrolled pain. The addition of as-needed or "rescue dose" to scheduled analgesia is appropriate for breakthrough pain.[19] This can be achieved by using one or more routes of medication administration.

Case Study: A Patient in Pain Crisis

Molly is a 12-year-old admitted to the hospital for acute vaso-occlusive pain crisis secondary to sickle cell disease. For the 48 hours prior to admission, she had been taking oxycodone 7.5 mg orally every 4 hours, with an additional oxycodone 5 mg orally every 1 hour as needed for breakthrough pain. She typically began this regimen at the onset of acute pain crisis symptoms. On admission, Molly and her father reported that she had taken 17.5 mg of oxycodone in the prior 4 hours with only minimal pain relief. She received heat packs to apply to painful sites, distraction with movies, intravenous hydration, and scheduled intravenous ketorolac, and was started on a patient-controlled analgesia (PCA) pump (morphine 1 mg/hr plus a 1 mg demand dose every 10-minute lockout) since she was complaining of upset stomach and was unable to tolerate any more oral medications. After several hours, she had improved pain control and was using her demand dose on average once per hour.

By the Appropriate Route

Analgesics should be administered by the simplest, most effective, and least painful route making oral analgesics preferred if possible. The intramuscular route is to be avoided given its painful administration. Alternative routes of administration, including buccal, intravenous, intranasal, subcutaneous, rectal, or transdermal, should be used when the oral route is not available or based on clinical judgment and patient preference.

Case Study: Varying the Route of Medication Delivery

Heather is an 8-year-old with spinal muscular atrophy who was preparing for hospital discharge following spinal fusion surgery. She had been hospitalized for 4 weeks and required high-dose opioids for pain control during her intensive care stay. The critical care unit had been reducing her intravenous hydromorphone doses over time to avoid withdrawal symptoms, without need for breakthrough dosing. Heather had severe gastroparesis at baseline and was dependent on total parenteral nutrition. She had a gastrostomy tube, but her mother reported that medications appeared to "just come right back out" when her gastrostomy tube was vented. The team decided to transition her from her intravenous hydromorphone to buccal concentrated morphine for home use and expected her to continue her opioid wean as an outpatient.

Treatment for the Individual Child

Consideration should be given to other sources of nonopioid-responsive pain and distress (emotional, existential, spiritual) and non-pain symptoms that children may report as pain (constipation, spasticity, gastrointestinal upset). Analgesic regimens should be multimodal, including both nonpharmacologic and pharmacologic strategies; combination therapy of nonopioids, opioids when necessary, and adjuvant medications for neuropathic pain may be utilized.[16] Analgesic regimens should target the primary source and pathophysiology of the individual child's pain. The child's age and ability to metabolize medications should also be considered. Opioid regimens should be tailored and titrated on an individual basis, taking into consideration a child's previous opioid exposure and response. There is no absolute maximum dose of opioids; the appropriate dose achieves desired pain relief with side effects tolerable to the patient and caregivers.

Neuropathic Pain

Neuropathic pain occurs when there is damage to a nerve either by chemical damage, nerve compression, or prolonged excitation. On physical exam, there may be autonomic changes to the affected area including changes in skin color, skin temperature, or edema. There may be sensory abnormalities (Box 64.2) and motor function changes (as evidenced by decreased strength or diminished reflexes). A child may describe a burning sensation, "prickling," numbness, tingling, "pins and needles," shock waves, or shooting pain. Some children may not have the vocabulary to describe neuropathic pain characteristics. Neuropathic pain can be constant or intermittent. Common causes of peripheral neuropathic pain in pediatrics include medications (i.e., chemotherapy), metabolic conditions, tumor compression of the nerve root, and nerve compression caused by musculoskeletal abnormalities such as scoliosis in neuromuscular disease. Recent surgery can be a risk factor for peripheral neuropathic pain. *Central pain syndromes* can occur as a result of a malformation or damage to the central nervous system. Children with severe neurologic impairment are at risk for neuropathic pain.[10] Severe neurologic impairment may result from injury (severe anoxic brain injury), congenital brain malformation (schizencephaly or lissencephaly), or metabolic disorders (mitochondrial cytopathy, Leigh's syndrome).

Box 64.2 Sensory Abnormalities Seen in Neuropathic Pain Syndromes

- *Paresthesia*: An abnormal (not unpleasant) sensation, whether spontaneous or evoked
- *Dysesthesia*: An unpleasant abnormal sensation, whether spontaneous or evoked
- *Allodynia*: Pain due to a stimulus that does not normally provoke pain
- *Hyperalgesia*: Increased pain from a stimulus that normally provokes pain

Neuropathic pain treatment is focused on decreasing the firing of the ascending pathways and increasing the descending or inhibitory pathways of the peripheral and central nervous systems. Gabapentin is most commonly used in pediatrics as it is available in liquid formulation and has a limited side-effect profile. In pediatric orthopedic surgery patients, gabapentin and clonidine have been shown to decrease postoperative opioid use, decrease hospital length of stay, and improve functioning postoperatively.[20] Serotonin norepinephrine reuptake inhibitors may be helpful for patients with neuropathic pain and comorbid depression. Methadone and ketamine (oral or intravenous) may be indicated when patients are experiencing severe neuropathic pain requiring opioids with minimal relief.[21] Table 64.8 details medications used to treat neuropathic pain; medications are listed in what would be a stepwise approach. The medications used to treat peripheral neuropathic pain and central neuropathic pain syndromes are the same. Concurrent treatment with physical and occupational therapy supports improved functioning and reduction in pain over time.[22]

Case Study: A Pediatric Patient with Peripheral Neuropathy

Brittany was a 17-year-old girl with leukemia who was hospitalized for continued chemotherapy. She had severe chemotherapy-induced peripheral neuropathy in her hands and feet. She cried when her hands or feet were lightly touched by her bed sheets. On exam, she was sedated, her hand grasp was extremely weak, and she was unable to stand due to pain and lethargy. She was receiving hydromorphone PCA of 1.5 mg/hr plus a 2 mg demand dose with every 20-minute lockout. Brittany was engaging in a function-focused rehabilitation plan with desensitization through physical and occupational therapy. Meditation, animal-assisted therapy and art therapy supported her coping with pain. She was receiving scheduled acetaminophen, oral gabapentin 1,200 mg three times a day, and clonidine 0.3 mg/24 hr transdermal patch. She had pancytopenia following chemotherapy and was thus unable to take NSAIDs. She was started on a ketamine infusion and achieved improved pain control within 24 hours. Over the course of the next week, the hydromorphone PCA was able to be weaned with

Table 64.8 Medications used in the treatment of neuropathic pain and chronic pain syndromes

Medication or drug class	Route	Dose	Titrations	Comments
Gabapentin (Neurontin)	PO	Start 2–5 mg/kg/dose qHS	Titrate every 1–4 days by 5 mg/kg/day until effective analgesia Minimum effective dose for children <5 years 40–60 mg/kg/day; children >5 years 30 mg/kg/day Maximum dose 50–75 mg/kg/day (2400–3600 mg/day) divided tid Children with severe neurologic impairment may require higher doses	Monitor for side-effects: nystagmus, sedation, tremors, ataxia, swelling May see increase fatigue/sleepiness when initiating or titrating May give 50% of total dose in evening if symptoms occur mostly overnight
Pregabalin (Lyrica)	PO	Start 0.3 mg/kg qHS Adults: 150 mg divided bid–tid	Titrate every 3 days to 1.5 mg/kg/dose bid (max 6 mg/kg/dose) Adults: titrate in 1 week to 300 mg divided bid–tid, max daily dose 600 mg	
Clonidine	PO, TD	Day 1–3: 0.002 mg/kg qHS	Day 4–6: 0.002 mg/kg bid; Day 7–9: 0.002 mg/kg tid	PO and TD daily dosing is equivalent, but TD patch takes 2-3 days to reach full effect Monitor blood pressure
Tricyclic antidepressants	PO	Nortriptyline: Start 0.1 mg/kg qHS, titrate up to 0.5 mg/kg, max 1 mg/kg		Nortriptyline has less anticholinergic effect than amitriptyline Given at night can help with sleep
		Amitriptyline: Start 0.1 mg/kg qHS, titrate up to 0.5 mg/kg, max 1–2 mg/kg		
Serotonin norepinephrine reuptake inhibitors	PO	Duloxetine: 20 mg qHS, titrate up to 60 mg QD, max 60 mg bid, cannot be crushed		
		Venlafaxine: 12.5–37.5 mg daily ×1 week, then bid, then increase by 12.5–37.5 mg every week, max 225 mg/day; immediate-release tabs can be crushed		
Methadone	PO, IV	0.1 mg/kg/dose q6-12h		Strong opioid with NMDA receptor channel blocker Long and variable half-life, 3–60 hours, requires prescriber to be skilled in methadone use
Ketamine	PO, IV	PO: 0.2–0.5 mg/kg/dose tid–qid[19] IV: 0.06–0.3 mg/kg/hr	PO: can titrate to 1 mg/kg/dose	NMDA receptor channel blocker Ketamine may reduce opioid tolerance allowing for opioid dose reduction
Cannabinoids	PO	Dronabinol (Marinol) 2.5 mg PO bid, max 20 mg/day		In some states, medical marijuana has been approved for use in pediatric patients

Source: Adapted from J. Hauer's "neuro-pain" ladder described in Reference 10, as well as the adjuvant analgesics recommended in Reference 23.

continued pain control, less sedation, and improved functioning. She was eventually transitioned off her hydromorphone and ketamine infusions and onto scheduled oral methadone, which was continued after hospital discharge and then slowly weaned over the next 3 months as her neuropathy resolved. She continued outpatient physical therapy and psychotherapy for support of her symptoms.

Chronic Pain

Pain is considered chronic if present for more than 3 months. It is often divided into two subcategories: *cancer pain* and *chronic nonmalignant pain*. Examples of chronic nonmalignant pain conditions seen in pediatric patients include avascular necrosis, musculoskeletal pain secondary to neuromuscular deformities, and abdominal pain in patients with inflammatory bowel disease. In chronic nonmalignant pain, pain persists even after the tissue injury has healed.

Treatment of chronic pain in children should use a multimodal approach, including interventions to address the physical and emotional impacts of chronic pain, such as pharmacotherapy, physical therapy, and psychotherapy.[23] The goals of treatment are primarily to improve function and coping because pain frequency may not change.[24] Improvement in daily functioning, mood, and sleep may occur over weeks to months with adherence to medication, exercise, and psychotherapy.

Opioids are appropriate for chronic use in cancer patients who have clear tissue injury or malignant disease. Opioids are not indicated for use in nonmalignant chronic pain and should be avoided given their limited benefit long-term, risk of side effects, and risk of abuse.[25] In nonmalignant chronic pain, pharmacologic treatment should target neuropathic etiologies[23] (refer to Table 64.8 for recommended medications). Children should be empowered to continue daily functioning despite pain and encouraged to maintain a healthy lifestyle with good sleep hygiene, daily exercise, and good nutrition. Appropriate referrals to physical therapy, occupational therapy, psychotherapy, and psychiatry should be made as needed. Comorbid depression and anxiety are commonly seen in patients who experience chronic pain and should be treated accordingly. Psychotherapy can be especially helpful for patients to learn and practice coping techniques such as guided imagery, self-hypnosis, cognitive-behavioral reframing, and progressive muscle relaxation. Grief support may be helpful if children have experienced a loss or an anticipated loss due to illness (e.g., loss of independence or functioning, amputation of limb, loss of normal childhood experiences, death).

Case Study: A Pediatric Patient with Chronic Pain

Alice was a 15-year-old girl (45 kg) with Charcot-Marie-Tooth disease and subsequent scoliosis and muscle weakness. She complained of several months of constant pain to her low back and right hip (sore, with shooting and tingling) and an intermittent shooting pain down her right leg. She took oral gabapentin 600 mg three times a day and diazepam at bedtime because pain limited her restful sleep. She also took oral oxycodone 5 mg every 4 hours as needed and as prescribed by her orthopedist; she used on average 1 dose per day. Alice was referred to outpatient physical and occupational therapy, massage therapy, and a psychologist for support in coping with her chronic illness and chronic pain. She was also started on oral amitriptyline 25 mg at bedtime to help with chronic neuropathic pain secondary to scoliosis, and the team hoped the anticholinergic effects of amitriptyline would also help Alice sleep. She was seen a month later in follow-up and stated that she saw an improvement in her sleep with the first dose and that her pain improved over the next few weeks in alignment with functional improvements brought on by concurrent physical therapy. She continued to take her gabapentin in addition to her amitriptyline but had not needed to use any diazepam or oxycodone in the past month.

Medical Marijuana in Pediatrics

Many states have adopted laws legalizing the use of medical marijuana, but it remains illegal based on federal law in the United States. Given this, there is a lack of research on the risks and benefits of medical marijuana in the pediatric population. Medical marijuana for children became popularized by case reports of its benefit in the treatment of epilepsy.[26] The use of medical marijuana for the management of pain is uncertain, and there are insufficient data to strongly support or refute its use for pain.[27] Parents whose children are suffering from refractory symptoms such as pain, muscle spasms, and seizures may be open to trying anything that may help. The nurse should know the status of the medical marijuana laws in his or her state, eligibility criteria, and the process to obtain medical marijuana. The patient and the family may want to consider consultation with a pain or palliative care specialist. Nurses should remain open to the conversation with parents/families as together we learn more about medical marijuana.

Conclusion

The plan of care for assessment and management of pain in children should be individualized, with an understanding of developmental and behavioral norms taken into consideration. Children and families facing serious illness desire to be engaged and empowered in their care, and the palliative care clinician should include them in order to best manage the child's pain. The common conditions seen in pediatric palliative care are different from the adult population: however, children still experience the same types of pain.

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CHAPTER 65

Supporting Adolescents with a Parent in Hospice

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Key Points

- Parentally bereaved adolescents are at higher risk for emotional and psychosocial distress than their nonbereaved peers.
- Family communication and support are critical to the adolescent during this time.
- The work of assisting adolescents with spiritual issues during and after the death of a parent will often fall to providers who must be able to recognize and assist adolescents in spiritual crisis.
- Despite the challenges of meeting and establishing rapport with adolescents, teens are interested in being involved with the hospice team.

Introduction

The National Hospice and Palliative Care Organization reported that approximately 175,000 people between the ages of 34 and 64 years died while in hospice care in 2012[1]; many had adolescent children. Adolescents struggle to process their "new world" that includes a dying parent during the final months of a parent's life, making this an especially stressful time for them.[2] Although parentally bereaved children may experience long-term effects, including greater rates of early mortality,[3] they are likely to show the greatest distress just prior to the parent's death.[4]

Adolescent Development

Adolescents whose parents are near the end of their lives are a unique population. While they experience the normal challenges of adolescent development, including rapid physical changes and concerns about their appearance, as well as developing their identity, establishing autonomy, seeking independence from parents, and focusing on peer and romantic relationships,[5] they are also experiencing the stressors of having a parent who is dying. Their homes are often transformed into "death's waiting room."[6] Other stressors include caretaking responsibilities, restrictions on time spent on school activities and socializing with friends,[2,7] witnessing the parent's symptoms and physical decline,[2,4,7] fear of abandonment and family dissolution,[2] isolation from peers, and attempts to maintain normalcy by suppressing or minimizing feelings of distress.[2,8]

Bereaved children are at a greater risk for emotional and psychosocial distress than nonbereaved children. Some of the most common psychological problems among youth facing parental death during the first year and persisting into the second year after the death are anxiety, depression, personality disorder, and posttraumatic stress disorder.[9,10] Gender and age have been associated with parental bereavement, with the highest rates of problems being reported by younger boys. Approximately 31% of bereaved youth exhibited increased grief reactions 9 months after a parent's death; the rate decreased slowly over time.[11] Children and adolescents with complicated grief or prolonged grief reactions showed higher levels of functional impairment.

Prolonged grief in youth and in the surviving caregiver predisposed the children and adolescents to an increased incidence of depression. Parentally bereaved children and adolescents were found to be at higher risk for major depression and alcohol or substance abuse 21 months after the parent's death compared to the normed group.[9] Bereaved youth with a history of depression were at increased risk of depression during the first 9 months following the death and at 21 months post death. Depression in the second year was found to be associated with losing a mother, blaming others, low self-esteem, negative coping, and complicated grief. Youth experienced more difficulties at work, less well-elaborated plans for career development, lower peer attachment, and diminished educational aspirations at 62 months post parental death.[12] When parentally bereaved children were not given clear and honest information during appropriate time points throughout their parent's illness and at the time of death, relevant to their understanding and experience, they experienced distress as children and adults.[13] When children and adolescents feel included and supported through their social network, distress is minimized.

Adults commonly want to protect children and adolescents from the pain of death, dying, grief, and loss. Western culture promotes the perception that if death is not discussed, the loss has less impact. However, death is a constant in the lives of adolescents. They are aware when plants, pets, and people die. Movies, television, video games, and books in school include themes and images related to death, which can reinforce illusions and misinformation about the topic by the teen years. Grief needs to be validated, and adolescents need to be supported. Often adults' hesitancy to discuss death with grieving adolescents isolates the adolescent from his or her own experience and from others.

Becoming independent, developing and maintaining friendships and relationships, and determining a focus for the adult world are paramount during adolescence.[14] Although teens have the ability to talk about their emptiness, pain, and hurt, they are often unwilling or unable to share these feelings with others. Feelings of grief may be intense and changeable, and the adolescent may fear these feelings. It is common for a grieving adolescent to experience decreased motivation or the ability to concentrate for long periods of time, making school work more challenging.

Teens have a cognitive understanding of and a philosophical, speculative interest in death. However, they are only beginning to grapple with it spiritually and often ask theoretical questions about what happens after death. They are able to distinguish between body and soul and engage in discussions about the deceased but often do not literally believe the dead go to heaven. Teens preoccupied with questions about life after death are sometimes skeptical of the existence of an afterlife. The death of a parent or someone close adds another dimension, as the teen might have just begun to appreciate this person from the perspective of a young adult like him- or herself. Furthermore, the death of the parent includes the loss of a personal history, continuity in their lives, and someone with whom the adolescent talked to and shared ideas, thoughts, and feelings.[15]

Adolescent Grief

The Harvard Child Bereavement Study followed 70 families for 2 years after the death of one parent. While the study has never been replicated, it is widely accepted among grief counselors. The study's findings include teens' increased levels of social withdrawal, anxiety, and social problems 2 years after the death. Mother loss was associated with more emotional and behavioral issues, especially for teenage girls. Children who adapted better were from cohesive families in which there was open conversation about the deceased parent. The most powerful predictor of adjustment was the functioning level of the surviving parent. Support, nurturance, and continuity were identified as three needs of the adolescent after the death.[16]

Anticipatory grief is often present when the parent is dying in hospice or is in palliative care. It can be present in the face of a chronic illness, where there is a continuum of losses including physical, functional, and cognitive decline as the disease progresses. Anticipatory grief does not take away or lessen the pain of grief after the death, but it does allow time for the family to come together. Thus, it can be a time for parents to talk about the anticipated death, address questions, and hopefully empower one another for when death occurs. It's a time to share feelings and concerns, and talk about and solve problems, as well as acknowledge that the death is not preventable.

Disenfranchised grief is not publicly acknowledged or socially sanctioned. The grief of adolescents is often disenfranchised, and they are frequently referred to as "invisible" or "forgotten mourners." The fear of social disapproval, of losing control, and peer perception of grief reaction impacts how adolescents express their grief. Parents create the social norms for the grief experience. Their belief or lack thereof about the impact of the loss can disenfranchise the grief.[17]

Secondary losses, which are physical or psychosocial losses resulting from the initial loss, occur with the death of a parent. These losses include not only relationship roles (confidant, companion, caregiver, etc.) but also intangible losses (dreams, hopes, self-esteem, meaning, and purpose). Sometimes the adolescent was the caregiver for the parent or played a smaller but still critical role in the household by engaging in chores, meal preparation, and care of younger siblings.[2,18] Teens may grieve the loss of that role. In addition, there are losses that occur over time. Adolescents revisit the meaning of their parent's death as they give away the parent's clothing, as memories fade, and as they experience their physical absence at significant events (prom, graduations, college selection, weddings, etc.). Each secondary loss results in its own grief reaction and needs to be mourned.[18] When others don't understand this grief process or reaction, the adolescent often feels unsupported.

Gender differences play a role in grief reactions. Males seem to be concerned with loyalty and solidarity, whereas females are more involved with meeting each other's needs. There are also differences in societal expectations about how children should behave. Early on, children learn their family's scripts and messages on how to react to a death. Girls are frequently given more leniency in expressing their feelings than boys, who may try to be more rational and logical. With traumatic loss, males may manifest their grief in expressions of anger and rage, whereas females typically turn their anger inward.[19] Regardless of gender and parental expectations, adolescents will grieve in their own way. Box 65.1 lists examples of the ways adults can support grieving adolescents.[20]

Telling Adolescents about a Parent's Life-Limiting Illness and Death

Telling adolescents about a parent's life-limiting illness and death is very difficult, especially when the family members struggle with communicating with each other.[21] Protecting the child from the potentially harmful effects of bad news is often a dilemma.[22] Worry and concern about the child's emotional reaction to a parent's imminent death may be a reason for lack of communication.[23] Healthy adaptation to parental loss is more likely to occur when families share information and openly express feelings of anger, guilt, and sadness about the deceased person.[20,24,25]

Parents communicate with their children in a variety of ways, ranging from neither parent talking about the impending death to both parents actively preparing the children for the death.[21] Limited communication often results when the well parent follows the lead of the ill parent until the imminence of death necessitates disclosure. Reasons for lack of communication between teenagers and their parents about a parent's imminent death include one or both parents and their teenage child pretending that the illness was not that serious and parents being unaware that death was imminent.[26] The spectrum of disclosure, covering ways in which adolescents were told about the parent's prognosis, ranges from saying nothing to saying the parent may die. However, often, adolescents speculate that their parent might die no matter what prognostic information they are given.[6,21]

Sheehan and colleagues[21] found that parents disclosed information about the progression of a parent's life-threatening illness and death that was intended to inform the adolescent and ease his or her distress. The process remained fairly consistent throughout the

Box 65.1 Ways to Help Adolescents Who Have Lost a Parent or a Loved One

- *Ongoing assessment*: Adolescents at high risk for complicated grief should be identified and monitored. Due to the prolonged and lingering effects of grief and grief triggers, reactions can manifest at any time.
- *Grieving adolescents need to share their story*: Adults can look for opportunities to listen to their story.
- *Peer support groups*: Because peers and friends are so important in this stage of development, adolescent peer support groups are very valuable. Members discover that their feelings are normal and that they are not going crazy. Hearing suggestions and receiving support from fellow teens has more power than from well-intentioned adults.
- *Literature*: Many books and movies focus on death and dying. Literature studied in high school classes frequently includes the death of a central character, thus presenting an educational opportunity for coping with grief and loss.
- *Writing may serve a therapeutic purpose for some adolescents who put their grief in words*: Putting thoughts and feelings in journals, letters to the person who has died, poems, and stories give grieving adolescents an avenue to express feelings.
- *Rituals*: Participating in a ritual that becomes a focus for the grief is helpful. Adolescents often incorporate music and slideshows into elaborate memorials. Rituals should be meaningful and are useful to help "say goodbye."
- *Legacies*: Maintaining a relationship with the deceased is valuable. By living a legacy of the deceased, teens not only remember their parent, but also feel they will be remembered themselves.
- *Music plays an important role in the lives of adolescents*: Communicating through music can enhance our understanding of grieving adolescents. Certain songs elicit feelings, thoughts, and memories related to the person who has died. Music can help adolescents share what they are experiencing with someone else and break through the defenses of grief. Adolescents may want to write original music as a tribute to the person who has died or select music that reminds them of their loved one and discuss the lyrics.
- *Art provides a creative outlet for grieving adolescents to create a visual image of their feelings and their story of grief*: They may want to create a legacy, such as a quilt or a memory box. These visual images can encourage communication and support a healthy grieving process.
- *Social media and technology*: Adolescents are high-volume users of social media networks. Learning about deaths in the community as well as sharing information about their own loved one's death is instantaneous in social media and through technology. Online condolences can be both helpful and hurtful. Monitoring the adolescent's usage has advantages and disadvantages. Adults need to be cognizant of the importance of social networks in this stage of development. Good information and support is available online, and more apps are constantly being developed to specifically address grief and loss, suicide ideation, anxiety, and other issues important to teens. Adolescents need to be reminded that information found online may be inaccurate and that anonymity may expose them to painful comments and predators.

Source: From Reference 20.

illness and after the death. Parents shared information in one of four ways in an attempt to make the illness and death "easier to swallow" for adolescents: measured telling, skirted telling, matter-of-fact telling, and inconsistent telling.

Measured telling. Measured telling occurred when the parent told the adolescent about the death in a way that was thoughtfully considered. Parents considered the adolescent's age and emotional state before carefully and rationally determining the nature, the amount of information shared, and the timing of the disclosure. Adolescents felt well-informed but not overwhelmed. The outcomes of measured telling were generally positive.[21]

Skirted telling. Skirted telling occurred before the death, when parents told their adolescents about the illness and imminent death of the parent in an indirect or ambiguous way. Parents did not lie or hide the truth from the adolescents, but they avoided revealing information directly. Parents bypassed difficult information to make the disclosure easier for their adolescent children. Adolescents acted as if the parent was not seriously ill and dying, and told their parents they did not want to discuss the illness. Parents and adolescents agreed about this way of communicating; they did not experience discord in relation to disclosure. Parents thought they were allowing their children to live as normally as possible, and adolescents were satisfied with the information they received. Outcomes for skirted telling were generally positive.[21]

Matter-of-fact telling. Matter-of-fact telling occurred when parents told the adolescent about the parent's life-limiting illness and death in a way that was unemotional and factual. These disclosures focused mainly on practical issues, such as caregiving needs, the death, and making funeral arrangements. These disclosures were described as everyday conversations, rather than as specific incidents in which parents "broke the bad news" to adolescents. Before the death, neither the parents nor adolescents specifically recalled the disclosure, because they were embedded in daily conversations. However, parents and adolescents vividly remember telling and being told of the death.[21]

Inconsistent telling. Inconsistent telling occurred when the parent told the adolescent about the death in ways that were changing and unpredictable. Inconsistent telling before the death involved a mixture of not telling, telling very directly, telling practical information, delays in telling, and telling information that was not true. No consistent patterns of disclosure could be discerned for these families.[21]

The quality of parenting by the surviving parent is one of the most influential resources for helping bereaved children adjust positively to the parent's death.[27] Clinicians can assist bereaved families with disclosure by tailoring strategies in accordance with the family's communication style. For example, families who disclose in inconsistent ways may need help in designing interventions to promote their parenting communication skills and coping. Creating group sessions for bereaved families could assist them in maintaining emotional stability to cope effectively with the stress related to informing their adolescent children about a parent's death.

Living in Two Worlds

Adolescents and their parents have described "two worlds" that constitute the lives of adolescents while their parents were seriously ill and shortly after their death: the well world and the ill world. The worlds had no physical boundaries; they were spheres in which the adolescents carried out practical, daily activities. Adolescents lived their "normal" lives in the "well world," attending school, spending time with peers, and engaging in social activities. They dealt with the life-limiting illness and death of their parents in the "ill world," spending time with their ill parents, visiting them in the hospital or hospice facility, providing care for them in the home, and taking on additional family responsibilities such as household tasks and caring for siblings.

They managed the two worlds in common ways across the duration of the parent's illness and death by keeping the ill world and the well world separate, having the ill world intrude into the well world, moving between the ill world and the well world, being immersed in the ill world, and returning to the well world having been changed by the ill world. They tried to keep their two worlds apart when the ill parent was initially diagnosed with a life-limiting illness. Adolescents wanted life to be "normal" and did not want to be seen as different from their peers.[2]

Keeping the two worlds separate. One strategy they used to keep the two worlds separate was staying busy with well-world activities to keep themselves from worrying about their parent's declining health. One 17-year-old daughter explained, "Being at school is a distraction because it gives me other things to do instead of worry about home, what is making me sad. At school it is like, school mode, [at home it is] home mode." Adolescents distracted themselves from the ill world by going to school, going out with friends, participating in sports, listening to music, writing, playing video games, sleeping, and maintaining their privacy. They also kept the ill world out of their well world by not revealing or discussing their parent's illness and by keeping their friends away from their ill parent. Adolescents who lacked a close relationship with the ill parent found it easier to separate the two worlds.[2]

When the ill world intrudes into the well world. The ill world intruded into the well world as the ill parent's health declined and the adolescent observed the parent getting weaker, changing in appearance, receiving more intense medical treatment, and becoming less able to accomplish daily tasks. Adolescents were especially distressed after a difficult incident, such as when the parent was brought to the hospice facility or something happened at home. During this stage, some adolescents began to accept support from concerned family and friends.[2]

Moving between the two worlds. Moving between the two worlds involved a sense of being vigilant as to when one needed to move from one world to another. The adolescents knew they may be called home from school or from a friend's house to help their ill parent. This was especially true in single-parent families.[2]

Becoming immersed in the ill world. As the health of their ill parents declined further and they grew closer to death, adolescents focused more on their ill parents and their families and gave up many of their well-world activities. They became immersed in the ill world by taking on caregiving responsibilities and spending more time with the ill parent.[2]

Caregiving responsibilities undertaken by adolescents of ill parents were in many cases considerable. Some did extensive household tasks, provided personal care for the ill parent, and cared for siblings. Although some adolescents appreciated the opportunity to care for dying parents and to "help out" their families, caregiving responsibilities could occupy a significant amount of time and feel burdensome. The responsibilities of having a parent near death were especially taxing for adolescents in single-parent families and for those in which the well parents worked outside of the home. Adolescents also became more immersed in the ill world as they spent more time with their families, often choosing to stay home just to "hang out" with their ill parents as they realized there was little time left. During these times, adolescents would offer emotional support and express affection toward the ill parent.[2]

Returning to the well world having been changed by the ill world. The final stage occurred after the ill parent's death and funeral, when adolescents fully resumed their well-world activities. Several adolescents emphasized, however, that they were fundamentally changed by the loss of their parent, and the well world was no longer the same. The well world was different because most others in the well world knew of their parent's death and therefore freely offered support and condolences. Feelings connected to others in the well world were now a comfort for most of the adolescents. Some connected through social media such as Facebook.[2]

Adolescents continued to feel the presence of their deceased parent, and thus many well-world activities were dampened by their sense of loss. They were painfully aware of the parent's absence at home and at athletic activities. Although adolescents continued to mourn the loss of their parents, several expressed a readiness to return fully to the well world, having grown through their loss. These adolescents had a sense that this is what their deceased parents would have wished for them.

Healthcare professionals can use the two-world model as a springboard to initiate conversations about how adolescents are managing their two worlds, explore which stage they are in, and help them decide how they wish to manage the tensions they experience in managing the demands of each world. The role of healthcare professionals and other adults who seek to help bereaved adolescents may change over time; adolescents may reject adult help when they are trying to keep the ill world out of their well world but welcome it when the ill world intrudes.

Adolescent Spirituality

Despite the fact that everyone undergoes spiritual development, spirituality itself is difficult to understand. Nearly every scientific manuscript about spirituality begins with the warning that spirituality has not been suitably defined for research.[28] Understanding spirituality as a phenomenon experienced by adolescents is no less challenging and is further complicated by competing demands of other cognitive, social, and physical developmental processes occurring at the same time.[29]

It is important for providers to understand that spirituality and religion are not equivalent and should not be used interchangeably.

Spirituality is a personal, unique, and subjective experience, and religion is a collection of dogmatic rituals and practices shared with others belonging to a specific community.[29] Viewing spirituality as religion risks alienating those who do not adhere to a particular religious view. This is especially true for adolescents who have not fully formed their religious beliefs. According to a recent Pew Poll,[30] Christianity is the predominant religion in the United States with 70.6% of those polled self-identifying as Christian, 20.8% of whom were Catholic. The same survey reports that 22.8% self-identified as having no religious affiliation and included atheists (3.1%) and agnostics (4.0%). Findings that those without a religious affiliation outnumbered the proportion of American Catholics underscores the importance of recognizing spirituality as an expansive phenomenon that consists of more than just religion. Stephenson and Berry[28] conducted an in-depth review of 40 original research articles to identify the common attributes that researchers used to describe or define spirituality for research. Five common attributes emerged from the data that overlapped to form the essence of spirituality. These attributes—meaning, beliefs, connections, self-transcendence, and value—will be used to frame spirituality for this discussion.

Adolescent Spiritual Development

Erikson described adolescence as a time when youth begin to think abstractly about transcendence.[5] This period aligns well with what Cobb, Kor, and Miller called a period of "spiritual surge"[31(p. 863)]—when adolescents reflect on the meaning and purpose of life events, the development of deep and sometimes romantic connections with others, and the exploration of religiosity. It stands to reason that children in the early stages of adolescent development will have reached fewer spiritual milestones and may struggle more with spiritual insight and expression.[31] This is generalized spiritual development, however, and should be weighed against the maturity and experiences of an individual adolescent.

Benson and Roehlkepartain[32] described adolescent spiritual development as dynamic, interactive, and difficult at times. Specifically, they described three nonlinear processes that adolescents undergo: an awakening to the larger universe around them, realization of their interconnectivity and identity within that universe, and eventual integration as an authentic member of the world around them. This explains how considerably the world changes from an adolescent's perspective of a limited and largely concrete viewpoint to recognition of an expansive and abstract universe in which they must somehow find their place. This shift in perception can be an overwhelming process that becomes more complicated with the death of a loved one.

Adolescent Exposures to Death

More than 2 million children under the age of 18 have experienced the death of a parent. As many as 90% of adolescents will experience what they consider to be a significant death.[29] Early experiences with death are especially challenging for adolescents who are still in abstract cognitive development. Witnessing the death of a loved one produces questions about God, meaning, and religion. Adolescents striving to find meaning in a loss can feel supported or distressed by thinking about spirituality, depending on their spiritual views at the time. Spiritual reflections about a loving God can have a calming influence for some adolescents, while others may feel anger, betrayal, or abandonment by the very God they are trying to understand.[29] Other variables are also associated with spirituality, including previous experiences, family traditions, and available support mechanisms.[32,33] King, Abo-Zena, and Weber[34] documented the importance of key relationships with others as being influential to adolescent spiritual development (e.g., parents, families, peers, community).

What happens, then, when an adolescent's significant relationship is disrupted, as occurs with the death of a parent? Hansen and colleagues[35] described how adolescents remained connected with their deceased parent after the parental death. The ways that adolescents preserved their continued bonds included using memories of their parent as an "inner guide" to help them navigate life after parental death, embracing opportunities to encounter their deceased parent through dream-like states, and collecting mementos of objects previously belonging to the parent. This supports other research showing how spirituality can offer protective benefits for youth at risk for problems associated with a significant death.[36–38] Additional research is needed to understand the role of and extent to which spiritual interventions can mitigate adolescent risky behaviors.

Assisting Adolescents with Spirituality

The spiritual literature describing the benefits of spirituality for adolescents is similar to that of adults. Adults and adolescents can reach out to religious and transpersonal authority figures when life becomes difficult. Dill[37] interviewed 20 urban African American adolescents about their spiritual and religious beliefs and found that participants used prayer to ask God to intervene on their behalf by correcting what they saw as being wrong with their life at the time. This presents new questions for adolescents who ask for divine intervention only to find that their prayers are not answered in the ways they expect. In research conducted to examine how adolescents managed having a parent in hospice a 17-year-old boy who was a self-proclaimed atheist admitted to experimenting with prayer to help his dying father.[33] The question of how this experience will impact the adolescent who already doubts the existence of God should be considered. What short- or long-term behaviors might manifest in response to his grief and disappointment? Holmes and Kim-Spoon[39] found that, among adolescents, a greater belief in an afterlife was associated with less participation in cigarette, alcohol, and marijuana use. Could this adolescent's disbelief in religion and afterlife forewarn the potential of future behavioral risks because of the loss of his father?

Many parents feel ill-prepared to help adolescents with issues they may not understand themselves, particularly when they are immersed in their own grief and suffering. Therefore, the work of assisting adolescents with spiritual issues during and after the death of a parent will often fall to providers who must be able to recognize and assist adolescents in spiritual crisis. Unfortunately, current evidence shows that dimensions of spirituality are often neglected by providers caring for families with adolescent children. Punziano and colleagues[24] conducted focus groups with hospice providers and found several challenges with delivering spiritual care to adolescents, such as the unique needs of adolescents depending on their spiritual development, views of an unacceptable death in a death-denying culture, the emergence of overwhelming negative feelings from the crisis to which the provider had to respond, and the long-term effects of loss. Deterrents from the family perspective included conflict between adolescents who wanted to do more for their parent while they were ill and parents who wanted to protect adolescents from the burden of care.

Adolescents' Interactions with Healthcare Providers

It is well-documented that adolescents with a parent in hospice are under stress and need ongoing support to cope with changing family dynamics and impending losses. In such cases, however, both the parents and patient's hospice/palliative healthcare team (HPHT) must face and overcome a number of obstacles in order to foster the kind of communication that helps teens survive and thrive during and after these pressing times. Researchers are now just beginning to report on some strategic approaches and training programs to help the HPHT reach out to teens in need as well as support parents to understand and respond to the emotional needs of their sons and daughters. In order to help refine these recommendations and ensure a good fit with what teens really need, it is important to hear how teens "size up" the HPHT and, as a result, either make themselves available and amenable or not to assessment and therapeutic interventions. Doing so may help formulate interventions that respond to teens' pressing concerns and counter any resistance they might have to working with the HPHT.

To better understand how adolescents "size up" and respond to the HPHT, researchers[38] interviewed adolescents (n = 30) with a parent in hospice and identified four types of teen–HPHT interactions: (1) no interactions (40%), (2) in-passing interactions (20%), (3) engaged interactions (20%), and (4) formal interactions. Analysis of each interaction type revealed different attitudes toward and appraisals of the HPHT.

No interactions. The most common type of interaction among teens and the HPHT was no interaction. Most indicated that they were away from home, either at school or busy with additional duties (working part-time or catching up on missed assignments due in part to adjusting to their parent's illness) during HPHT visits. When they were home, teens avoided the interaction, assuming that the HPHT's job was to take care of the sick parent and not knowing how to start a conversation and express themselves in order to get the support they needed.[38]

No interactions were a product of other factors as well. Parents may be motivated to protect their children from knowing too much about the severity of a parent's illness and may withhold both information and access to those with information to make the situation appear normal and thus more manageable. Also, teens may present themselves as doing fine in order not to worry and burden the sick parent, despite their potential need for additional care and support. Furthermore, hospice/palliative consults and care requests are often late referrals, leaving little time to assess and work with other family members in addition to the patient. HPHT daily schedules are often full, which forces individual visits to be time-limited and almost by default exclusively patient-focused. Additionally, HPHT members report that they do not have the skills nor do they understand how to assist grieving adolescents and, as a result, fear that they will not have the time to adequately assess and provide needed therapeutic support given the ever-pressing time constraints.[38,40]

In-passing interactions. One step further than no interaction, in-passing interactions occurred when teens were present for at least a brief period of time when the HPHT was providing clinical care to their dying parent. Like the "no interaction" group, teens often left early or arrived late due to conflicting schedules and had little-to-no time to connect with the HPHT provider. Conversations that did result were often brief updates on how the parent was doing or about changes to their status or care. Despite the brevity and lack of focus characterizing many of these encounters, adolescents were often left with the impression that the HPHT was approachable and could be called upon later if needed.[38]

Engaged interactions. In contrast to in-passing interactions, engaged interactions were typically ongoing and of longer duration. Teens and HPHT members were able to find and build on common ground and/or perceived shared similarities. With this foundation in place, teens reported being more relaxed as they developed trust in and felt they could rely on the HPHT member to provide guidance on how to cope with as well as support their dying parent.[38]

Formal helping interactions. The final group reported that the HPHT referred them to healthcare professionals to help with adjustment problems to their parent's illness. These professionals included art therapists, bereavement specialists, and counselors. To the degree that these referrals were on target to meet teens' needs, it appears that the HPHT was able to arrange a sufficient number of interactions to develop a workable relationship to conduct an assessment and develop enough trust to encourage teens to follow through on their recommendations.[38]

Facilitating and Improving Adolescent–HPHT Interactions

Despite the challenges of meeting and establishing rapport with adolescents, teens are interested in being involved. Alvariza et al.[41] report that teens want "1) to be seen and acknowledged; 2) to understand and prepare for illness, treatment, and the impending death; 3) to spend time with the ill parent, and 4) to receive support tailored to the individual teenager's need."[40(p. 313)] To begin, it is important to strategize how to initiate contact and maintain ongoing interactions with adolescents in order to allow the HPHT the time to make assessments and provide whatever therapeutic interventions and/or referrals are needed. Some preliminary work is needed to identify when teens are available to allocate sufficient time to meet and get to know them. Learning about their interests as well as concerns beforehand from parents or other adults in the family helps establish some common ground that may be used to "break the social ice" and ensure a good first impression that the HPHT member is approachable and available.

In addition to establishing and building rapport with teens who have a parent receiving hospice services, HPHT members must have proper training to ensure that the interactions are of sufficient quality to engender the trust needed to provide therapeutic support. The HPHT needs training to be able "to understand normal development, appreciate common grief responses and identify deviations" as a prerequisite for decisions regarding which supportive strategies and resources are appropriate for this age group.[41(p. 275)]

For the HPHT to support grieving adolescents, it is important to understand the psychosocial development of teens in a larger context. According to Erik Erikson's stages of psychosocial development,[5] teens are at the "identity vs. role confusion" stage in which individuating and establishing an independent sense is of primary importance. Losing a parent at this time can be particularly troublesome and anxiety-provoking as teens lose the "mirror" formerly provided by the parent to reflect back to them a sense of self.[42] HPHT must provide support to help teens cope with the loss and, at the same time, engage in the process of reconstructing a new life. In helping with this process, HPHT members will encounter a number of issues that teens will need to confront. Punziano et al.[24] conducted focus group interviews with health professionals to understand their experiences of providing supportive care to teens who lost a parent. Eight therapeutic themes were reported, including the reality of the loss as unthinkable, the loss generating negative emotions, the loss freeing up resources, the loss taking time to process, the loss becoming a catalyst for change, an authentic relationship as central to the loss, being present in the loss, and competent help for dealing with the loss. Navigating these issues with the teens requires the HPHT to strike a balance between addressing the impending loss while encouraging the adolescent to develop an independent sense of self. Attainment of these goals has been shown to improve both the teen's current and future mental health and psychosocial functioning.

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CHAPTER 66

Use of Social Media as a Communication Tool for People with Serious Illness and Their Families

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Key Points

- Social media provides a modern venue for people with advanced serious illness to tell their illness stories.
- Social media provides a venue for people with advanced serious illness to receive support from others.
- Social media provides another way for people with advanced serious illness to communicate with others.

Brief Social Media History and Impact of Social Media

With Web 2.0 came the creation of user-generated content and web-based interaction,[1] which has led to the development of a variety of social media platforms. The advent of this technology has influenced human interaction for individuals and communities; we now interact in ways we could not comprehend just 15 years ago. As the technology evolved, we developed algorithms that facilitated social networking sites to create an interconnection of platforms, which has led to our culture of connectivity.[2] Families with a loved one with serious advanced illness seek support, and social media provides this venue.

Over the past 15 years, use of the Internet and social media has skyrocketed. Today, around 32% of the world's population has Internet connection; in 1995, it was less than 1%. The first billion Internet users were reached in 2005.[3] At the time of this writing (December 2017), more than 4 million blogs and 570 million tweets were written or sent, and close to 2 million people were active on Facebook.[3] Current examples of social media are Twitter, Facebook, YouTube, Tumblr, and Pinterest.[4] To further define social media, the categories listed in Table 66.1 have been offered by Carrigan[4] and van Dijck.[2] In addition, Hootsuite, a social media management platform, offers categories to facilitate our understanding of these sites and why they are used.[5] It is important for the palliative care team to be aware of the types of social media available to patients and families because of their importance as a method for communication during advanced serious illness.

Social media affects multiple aspects of our lives, including the words we use and the meanings they have. Most people know what is meant by social media, Googling, or tweeting. Words like "friending," "sharing," and "liking" have newly understood meanings.[4] The term "well-connected" used to refer to a person of a certain social status; now, it could refer to many followers on one's Facebook page. On social media, these followers indicate "connections" or "friends" and do not discriminate between a close friend versus an acquaintance. For example, a Facebook "friend" may be an acquaintance from high school with whom there is very little interaction in real time. In addition, many close friends and family may also be denoted as "friends" on a Facebook page. In this way, there is no differentiation between family, close friends, and acquaintances with whom there is no face-to-face interaction.

Social media is changing the nature and structure of communication and interpersonal connectivity and serves as a method for obtaining social support, especially during times of crisis or difficulty. The Internet allows for interpersonal, participative, and interactive exchanges of information in a variety of ways, including blogs, Facebook, and Twitter.[6] A theoretical view provides more insight into the evolution of social media related to health and healthcare.

Theoretical View

Researchers have adopted many different theoretical frameworks to study the impact of social media on our everyday lives.[7] Frequently cited theories in this category include Social Aspects Theory, Social Capital Theory, and Social Power Theory. Mass communication theories try to explain the influence of social media on people's behavior. Para-social Interaction, Uses, and Gratification Theory (UCT) highlights this category. However, Social Capital Theory will be examined in depth to understand the role of social media in illness, including research of serious illness such as cancer.

Table 66.1 Categories of social media

Category	Purpose	Examples (not an exhaustive list)
Social network sites	One of the oldest forms of social media Promotes interpersonal contact between individuals or groups Often personal, professional, and geographical connections	Facebook, Twitter, and LinkedIn
User-generated content or media sharing networks	Supports creativity and exchange of amateur or professional content Provides a place to find and share media	YouTube, Instagram, Snapchat, Vimeo, and Flickr
Discussion forums	Older type of social media Used to find, discuss, and share news, information, and opinions	Reddit, Quora, and Digg
Blogging and publishing networks	Regularly updated website or web page Maintained by an individual or small group Can be personal updates and reflections, photos, etc. Often written in a diary style (blogs)	Wordpress, Tumblr, and Medium
Book marketing and content curation networks	Discover, save, share, and discuss new and trending content and media	Pinterest and Flipboard
Trading and marketing sites or social shopping networks	Exist to exchange products Provide comments and experiences from other shoppers	Amazon, Fancy, and eBay
Interest-based networks	Connect with others around a shared hobby or interest	Goodreads, Houzz, Last.fm
Consumer review networks	Find, review, and share information about brands, products, and services as well as restaurants and travel destinations	TripAdvisor, Yelp
Play and game sites	Host games that are social	Angry Birds, Farm Ville

Social Capital Theory

Broadly speaking, *social capital* is the amount of resources accumulated through relationships among people.[8] In Social Capital Theory, *bridging* and *bonding* social capital is discussed. The *bridging* social capital is the weak tie, and the *bonding* social capital is the strong tie. Finally, *linking relationships* refer to the relations of respect and trust between people who interact across power or authority differentials, such as the relationship between teacher and student or physician and patient.[9(p. 655)] Ultimately, the more social capital one has, the more resources and personal relationships one enjoys. Social capital refers to "features of social life—networks, norms, and trust—that enable participants to act together more effectively to pursue shared objectives."[10(p. 56)] The underlying idea of social capital is based on forming social networks. Therefore, people join social networks to form systems, such as social support during serious illness, which they were unable to attain on their own.[11(p. 1)]

In the case of palliative care, people with serious illness may build their social capital by seeking support through social media. Later in this chapter, we will discuss the benefits of people with serious illness connecting with others through illness blogs or other forms of social media such as Facebook. This type of social support is emerging as a valuable resource for the ill person and their family.

The influence of social capital relies on the ability to access and use resources within a social network. This, in turn, facilitates flow of information, influences decision-making, and provides different forms of support for an individual as a member of a social group sharing similar interests and resources.[11] Therefore, the more people one knows and the more relationships and connections one has within a social network, the more resources one can access to, consequently, achieve higher levels of social capital. More importantly, quality matters more than the number of relationships and resources available within a social network, consistent with the proverb, "It's not what you know but who you know that counts."[12(p. 264)] The dynamic interactions of Social Capital Theory can offer insight into the capabilities of a social structure to influence people's behavior within a social network.[13]

Social Media and Social Capital

Social media usage for enhancing personal relationships is a remarkable revolution of the modern era.[14] More importantly, it provides another venue for people with an advanced serious illness and their family to receive support, and it provides new ways to experience intimacy, friendship, and identity in which people can share their experiences with each other in a public display.[14] Social media provides a rich venue for people to share and exchange their experiences, interests, or views regardless of their racial, sexual, or religious identities.[15] Many Internet-based social media applications are available such as Facebook, blogs, Twitter, or Instagram. These applications allow people to share and exchange information using different platforms from texting to photo- or video-sharing.[15] Therefore, social media can be beneficial in building social capital via social networking. Social media has the potential to develop social capital by allowing people with a serious illness to establish and form new social relationships with others or to strengthen preexisting relationships within a social network.[8] This will lead to greater levels of social connectedness,[16] social support,[16–19] self–esteem,[20] experience-sharing,[21,22] management of burdens,[21,23] fostering of awareness,[24] decision-making,[25] and life satisfaction,[26] all of which are important outcomes for both the ill person and family.

The Power of Storytelling

Human beings are storytellers by nature, and the benefits of storytelling in healthcare are increasingly being recognized.[27–29] Storytelling as a fundamental component of nursing knowledge is a long-standing tradition.[30] Social media, in its various forms, also provides a venue to tell a story. In the case of a serious illness, the patient and family receive supportive and often useful comments from their social network in response to the story they are publicly writing on social media. As a narrative communication strategy, storytelling is useful in understanding experiences and communicating health information in an understandable manner with therapeutic health benefits for the teller and the listener.[21,27,31] Therapeutic benefits of storytelling in palliative and hospice care include being heard and creating a shared sense of purpose and connection to others. The sense of purpose (or sense-making) comes through the sharing of the story, and the ill person and family find a new purpose, sometimes described as new self.[32–34]

Social Media and Illness Key Characteristics

Social media expert danah boyd[35] describes the characteristics of social media: persistence, visibility, spreadability, and searchability. Hansen, Sheehan, and Stephenson[36] conducted a phenomenological study exploring the family caregivers of people with a serious advanced illness and their experience with illness blogs. Exemplars from this study demonstrate the following characteristics as described by boyd.

Persistence means that the content of social media is not forgotten. Conversations linger and provide a written history. For example, one participant commented about keeping her loved one's blog "alive" after he died. The content is not forgotten and is a powerful comfort to the surviving loved ones:

> I don't spend quite as much time on it . . . I kind of got it [the blog] at a stage where it gets regular traffic. . . . I guess that ties in with just grieving and wanting to keep things going. When he was doing it [writing the blog] I was kind of like his assistant and it was a team thing and I'm still part of the team, and I'm here, and I'm gonna keep it going.

Visibility refers to the accessibility of the content. In terms of communication of one's illness over social media, the accessibility of these sites increases the ill person's social network. Hansen, Sheehan, and Stephenson[36] found that many family caregivers commented on how their loved one's blog gained support from all over the country or sometimes even the world:

> Well, I think it has a benefit for me [the caregiver]; I feel the support and love she has out there with people I don't even know, that she doesn't even know. I mean, she's got over a thousand followers all over the world and I would say most of them don't know her but they've come across her blog. I think for me, it gives me a sense of hope that you know, she's on a mission.

Spreadability refers to acts of sharing that frequently occur on social media platforms, thus creating a situation known as "going viral."

> Many of them read her blog; either they found it on a Google search or learned about it through the forums [on websites], and it [the blog] became quite well known within the forums. There's not a comment about her, especially at the end, that didn't mention her blog and how it helped them.

Finally, *searchability* simply means the user-generated content on the Internet is searchable; therefore, even if the content has not spread, the content can be found. Hansen, Sheehan, and Stephenson[36] found this was true among their study participants:

> It [the blog] seemed to come up very easily on searchable indexes or Google; searching for some keywords with ovarian cancer and certain treatments seemed to come up with her blog all the time.

Understanding these characteristics as described by boyd helps explain why communicating with family and friends about a serious illness while in palliative and hospice care can be so powerful. The key characteristics of social media allow for sharing of information, mobilizing social support, and fostering self-expression, which are particularly important to individuals with severe illness. Social media can address feelings of isolation as well as reduce the experiences and symptoms of loneliness and depression for some adults facing a serious illness.[37] While any social media forum can be used to communicate one's illness, the following content focuses on illness blogs, Facebook, and Twitter. There are similarities and differences among these venues; however, blogs and Facebook are most similar when used to tell an illness story (Table 66.2).

Types of Social Media Used in Illness

Illness blog. The use of social media in healthcare has also grown rapidly among patients and caregivers.[38] A quick Google search for cancer blogs elicited 51,000,000 results, indicating that even difficult and stressful conversations are occurring on social media. Blogs initiated by patients or caregivers during treatment of a serious illness have increasingly become a way for individuals to give voice to their unique experiences as well as seek support from others in similar circumstances.[39] An illness blog is the story of one's illness posted on a social media platform which, when read and/or responded to by the family, has the potential to increase the social network and support for both the patient and family by increasing their social capital or resources.[40] Although an "illness blog theory" has not been posited in the literature, Heilferty[41] advanced the science with a concept analysis of illness blogs focusing on their applicability to nursing research and the interaction between family and patients. The author reported a theoretical definition of an illness blog as "an online expression of the narrative of illness."

Writing about one's illness on a blog has shown positive results for bloggers, including increased connection with others, decreased isolation, and more opportunities to tell their illness stories.[36] In addition, illness blogs have been found to promote accountability (to self and others) and create opportunities for making meaning and gaining insights from the experience of illness, nurturing a sense of purpose, and furthering understanding of their illness.[42,43] Furthermore, there are potential benefits to family caregivers who interact with their loved one on the illness blog in addition to their daily activities. According to Hansen, Sheehan, and Stephenson,[36] the illness blog, for the family caregiver, becomes a tool for communication and connection with the ill person, which leads to face-to-face conversations and comfort and hope for positive outcomes.

Facebook. Facebook is a Web 2.0 interface designed as a gathering place for its subscribers, where people who may be no more than acquaintances or even strangers become friends. For example, Gage-Bouchard, LaValley, Mollica, and Beaupin[44] reported that interaction on Facebook provided a venue to express cancer-related stories, promote advocacy, and obtain social support. Interestingly, Facebook social support was significantly related to general social support.[18,19] Participants valued the support they received from

Table 66.2 Examples of posts from select platforms

Illness blog, mother of four, breast cancer Published with permission, 10/26/2017	NED!!!! No! Evidence! of Disease! Cancer-Free! Complete Pathological Response! These were the words we heard today from our Super Surgeon, PRAISE GOD!!! The pathology came back clean. Clean lymph nodes. Clean margins. Clean breast tissue. *Chemo did its job! Cancer is nowhere to be found!* These are the words I have dreamed of hearing. And hearing them caused a wave of emotion in me – relief, happiness, thankfulness, awe, and then of course, the tears. Everyone was just happy today. Our doctor said this is the best kind of news to deliver. She looked so happy. Amazing Nurse Practitioner stopped in to say hi and share in the joy. The nurses were all so cheery. Our oncologist is in the Philippines for the next two weeks so I couldn't run up to him and give him the big bear hug that I imagined doing in my mind. At one of our appointments, as our doctor marveled at my shrinking tumor, he said there is a 30% (my husband heard 32% so that's still up for debate) chance that the tumor would shrink to nothing. Nothing. He said we wouldn't know until surgery, but the way he smiled, I knew he was hopeful. I heard him say these words and all I could think of was *there is a chance that the tumor could shrink to nothing. NOTHING.* In that moment, hearing him say those words, I told myself that would be ME. God willing, I would be part of this 30% club. Let's DO THIS! It's been an *awesome* week. It's been a surreal week. I am thanking God for carrying me through the toughest parts of this journey. There were many, many days when I know there was one set of footprints in the sand because I could no longer walk and he was carrying me. We have more decisions, and big ones at that, coming up regarding radiation and some genetic information that we are just learning about. This journey is far from over. I am healing from surgery. Tonight I am going to enjoy watching my girls do a little hip hop number at the high school basketball game. I am also anxiously awaiting joyful news of a new niece or nephew. Most of all, I am smiling from ear to ear that I am officially *NED*! December 3, 2013 has been added to the list of my all-time favorite dates! *Rejoice in the Lord!*
Illness story on Facebook, child with stage IV neuroblastoma With permission, 10/26/2017	I'm watching my son sleep for what we hope and pray is his last night ever on the Hematology/Oncology/Transplant HOT unit. If all goes well, we can leave on Fri night after he is unhooked from his final infusion. My husband came by tonight and the three of us hung out, played, and finally snuck out into the halls after his pca (pain meds) were done for the night. We reflected on how different things are now from our first night here on HOT. That day 14 months ago my son came out of day surgery for his cvl placement and we were taken directly up here. My husband and I were terrified. Still in shock of the diagnosis. Wondering what in the world we were getting into. Scared for the future. Feeling certain there had been some kind of mistake. This couldn't be happening to us. To him. To our baby boy. That night the nurses came in and hooked up his brand new cvl to lines and a pole. Our vocabulary quickly expanded to include words like "tubies," commode, Insuflon, dressing (not the salad kind), the hard to pronounce names of various medications, and more. It became commonplace to see nurses in the big "Cookie Monster" chemo gowns. Sleepless nights. Vitals. Beeping machines. At the end of that first week and still glazed over, we were scared to go home after our initial week-long hospital stay, because now *we* would suddenly be in charge of flushing lines, administering medications, and watching for fevers. It was like the terrifying feeling of bringing home your firstborn, only worse. And yet over time, this place became comfortable in a weird way. We got more efficient with packing each hospital stay as we learned what we wanted and needed in our room to make the tiny space home. The nurses became friends and then family we looked forward to seeing. We found playmates and buddies whom we looked forward to seeing on the floor when our stays coincided. We became experts at pushing around giant iv poles, stepping over a million iv lines, moving furniture 100 times a day to accommodate tents and toys in our small space. Eli stopped crying when we told him it was time to come back to stay at the hospital for a while. Instead, he started planning what he would take and what he would like to do while he would be there. . . .
Illness-related content on Twitter (Diddy & Lundy, 2017)	Does anyone feel like they are running up a sand pile, trying to push awareness to action during October? Just me? #bcsm"

Facebook friends and followers as much as the support received by family and friends in their daily lives.

Facebook has also been used to support bereaved caregivers through a hospice online support group[45] in which caregivers sought help for healing from their loss. Online support was found to be useful and as effective as face-to-face support groups. Furthermore, social support in many forms has been found to benefit cancer patients. Valle and colleagues[46] found that Facebook is a beneficial way for young cancer survivors to exchange health information and receive support, especially in promoting physical activity.

Twitter. Seeking health information and online support is commonplace and has been studied from numerous perspectives, including health information-seeking behaviors, predictors of eHealth usage, and the use of Twitter to disseminate health information.[47–49] Twitter is considered "microblogging" because it allows only short messages; therefore, the stated content is often simple. However, a good tweet invokes both emotion and information.

Research on social support through Twitter focuses on health outcomes and behavior change interventions such as weight loss[50,51] and smoking cessation.[52–55] Research examining serious illness, such as cancer, on Twitter is sparse. However, some studies focus on cancer patients. In a social support intervention through Twitter for cancer patients, Nam[56] discovered that bonding social capital had a strong, positive influence on achieving positive health outcomes. In addition, the Twitter-based social network system intervention had a significant direct effect on achieving positive health outcomes.[57] Based on current health-related Internet research, Twitter is a rich source of health information used by its members to seek health information, change health behaviors, and engage in illness-related discussions.

Social Media and the Family

Social media connects families in many ways. There is some evidence that social media can be a mechanism to enhance certain aspects of family interaction. Discussion about one's serious illness over social media can help open doors for difficult conversations, provide a charted course of what has happened over the duration of the illness, and lead to new avenues of support for and from others.

> And so it was just like oh, you know, that's my man, you know, and that was one of the most amazing things about it was that in that dark time when he was being stripped of everything, there was this one thing that had grown (his writing); it wasn't going away, it was coming, this new skill had been created or discovered.[36]

Enhancing Family Communication

Healthcare providers often think of difficult conversations taking place between the patient, family, and provider. However, difficult conversations also occur between patients and the family caregiver. When loved ones write about their own fears regarding their illness, it can invoke the same emotion in the family caregiver. Examining communication as a factor in the patient–caregiver dyad is crucial to the patient's and caregiver's quality of life.[58,59] However, the illness story also opens doors for further communication, as illustrated by the following participant comments.[36]

> Reading about his fear kind of made that more real for me; there was something about reading when he would write about this thought makes me really scared and would clue me into what was really bothering him if he hadn't been able to articulate it to me.

Reading a loved one's comments on a blog allows the family caregiver to reflect on the message before reacting to the written words, unlike a face-to-face conversation in which an immediate response is usually required. Other interpersonal behaviors, such as the involvement of the family caregiver with the ill loved one, may also affect how difficult conversations are initiated and continued throughout the illness trajectory. Some research suggests that when communication and sharing occur among family members, there is a sense of relief from emotional turmoil or even the desire to rebuild a crumbled relationship.[60,61] Hansen and colleagues[61] found that patients valued family members who were involved and reported high levels of comfort with that involvement. Furthermore, low-energy activities are better tolerated and appreciated by patients with a serious illness; therefore, interacting through social media may be well-accepted as an intervention.[61]

Difficult conversations are filled with a variety of emotions that are challenging, albeit critical, to the patient and family caregiver's well-being. When a family caregiver is first able to get a glimpse of how his or her loved one is coping with the illness or approaching decisions that lie ahead, it can open a door for further face-to-face conversations. One participant shared that "sometimes it is easier to write it than to talk about,"[36] indicating that the written story makes problems related to the illness easier to talk about later, after both the patient and the caregiver have a chance to think about what was written. Another participant remarked how his wife would write about her "feelings, fears, and what was going on" which they would discuss after her posts.[36] This interaction is comforting and presents one way for family caregivers to feel like part of the team.[36]

Facilitating Sense-Making

The written word detailing the illness story on social media is a document that tracks events in addition to experiences. These stories offer a method for developing interpretations of events.[62] The development of interpretations facilitates sense-making through a sequential interlacing of past, present, and future events.[62] The stories also facilitate dialogue around the meaning and purpose of the illness.[34,36,38] Hansen and colleagues[36] found that participants appreciated the written "track record" as a valuable aspect of the illness blog. The following exemplars demonstrate this phenomenon.

> She went through the standard National Comprehensive Cancer Network (NCCN) guidelines for treatment, and we were very on top of things, reading, and learning about stuff and in particular, that was sort of my primary role, coming up with ideas with the doctors and talking to other people, patients. What it ended up being [the blog] was a record of the treatment. She had about 27 regimens during her treatment, many did not work and most of them were outside of standard care.
>
> For her, it [the blog] was kind of cathartic to write what's on her mind, how she's feeling but also how she's approaching things and how she's approaching uncertainty with regimens or new regimens or vacations or stresses with family and life.

Family caregivers can also find clues in the illness story about how their loved one wants the illness and corresponding situations handled. In this way, social media can offer insights and clarification to the family caregiver's role.[36] For example, one man commented on how the blog provided a better understanding of how his wife wanted things handled,[36] explaining ". . . it let me have a glimpse into how she would like things handled and clearly, gloom and doom were not in our playbook."

When faced with uncertainty, the ability to create meaning or make sense out of a difficult situation becomes paramount.[63] As the patient and family caregiver navigate their way through the disease trajectory, they face uncertainties ranging from initial diagnosis to the prognosis, treatment, and side effects. When they use their stories to make sense of what is happening, they gain clarity and meaning.

Garnering Social Support

Typically, the end of life is thought to be shadowed by isolation and loneliness; however, caregivers find that, through social support, a balance of caregiving and burden is found because the ability to cope is improved.[32,36,58,59] In addition, research on social support demonstrates that close personal relationships assist in improving well-being, even in the absence of stress.[58,59] One method of support is through sharing an experience via social media. For example, a participant communicated about how she and her husband with a serious illness shared moments.[36]

> And then, start up in the middle of the night came all the comments. He got loads and loads of comments, and he loved . . . he kind of fed off those. . . . And that was something that we shared together. . . . I might wake up and he'd go oh, I've got five comments and we read them

> together and so it's kind of sharing the process with him and because we did it together it felt like it was support for both of us.

This statement exemplifies how communication through social media (in this case an illness blog) provides support for both the ill person and his or her family.

Support can also be derived through social media from others who have shared similar experiences. For example, one family caregiver stated, "the most important thing I think captured on this blog is how it helped other cancer victims and patients."[36] Kim and colleagues[64] reported the experiences of young adult cancer patients as described through online narratives via the website Planet Cancer. Over a 1-month period, 168 posts from blogs written by 12 males and 34 females were collected and analyzed. Ten main themes were reported: topics ranged from physical and psychological isolation to cancer survivorship. Researchers concluded that the online blogs provided a venue for sharing stories with those of similar ages and situations. Additionally, blogs served as a medium to combat social isolation when faced with physical disfigurement. A study using a sample of young women with cancer examined the use of complementary therapies.[65] Through analysis of the illness blog content, the authors reported the emergence of positive themes regarding complementary therapy use for symptom burden. This method of online communication provided an avenue to share information about complementary therapies and glean social support from women of similar ages with a cancer diagnosis.

Another study examined 24 illness blogs from Australia, Canada, the United Kingdom, and the United States written by men and women of different ages and with a range of cancer diagnoses.[66] One of the most distinguishing features of the blogs was the production and management of personal affect through self-expression about the impact of illness on the body and everyday life. The authors also describe the value of the blogs not only as a "communicative labor" but as a "network-enabling and social" labor. Bloggers generate online spaces where experiences can be shared, which ultimately impacts the broader social understanding of their illness.

Leaving a Legacy

As another means for support, social media may serve as a living memorial after a person dies, also known as a *continued bond*. Continued bonds assist those mourning the death of a loved one with creating meaning out of their loss and adjusting to life without their beloved family member or friend.[59] This is illustrated by a man discussing his wife's blog, who reported that "This [the blog] was helpful; her life was important and it's like a living memory or memorial for her."[36]

Pennington[67] discusses how students who have lost a loved one use Facebook as a living memorial. The author highlights the importance of Facebook in facilitating a continued bond with the deceased loved one and supporting sense-making and coming to terms with continuing the ties versus letting go, facilitating the grieving process, and moving forward. Keim-Malpass, Adelstein, and Kavalieratos[68] also found posthumous responses on illness blogs. The blogs in their study served both legacy-making and grief-processing functions. They found that posthumous responses included expressions of grief such as videos, obituaries, and communication via Twitter. Other studies support the use of social media in maintaining a continued relationship with the deceased loved ones. Degroot[69] found that written communication on deceased individuals' Facebook pages serve the function of sense-making and continued bonding for family members.

Social Media and Healthcare Providers

Healthcare providers use social media for both personal and professional objectives, with usage rates approaching 90%.[70] Although there is a great deal of variability in the use of and engagement with social media in the course of their professional duties, a smaller majority of providers (67%) use social media in a professional capacity.[70] The driver of professional use has been online professional communities aimed at sharing domain knowledge, keeping up with new developments, communicating with colleagues, or listening to experts.[71] This type of professional interaction and sharing was formerly reserved for regional and national professional meetings that occurred infrequently and required travel. The use of social media for professional education and collaboration has diminished geographic and time restrictions for dissemination of knowledge, collegial discussions, and networking.

Attitudes of healthcare professionals toward the use of social media in communicating with patients and families vary. In general, younger practitioners are more likely than older practitioners to have a favorable view of social media and use it to interact with patients.[72,73] Furthermore, there is some discordance in the motives for using social media in healthcare of professionals and patients.[71] Professionals tend to use social media for communicating with colleagues and marketing, whereas patients tend to access social media for healthcare information, advice, and social support. Regardless of usage motives, a majority of healthcare providers perceive social media as beneficial to their patients.[71] Some of the identified benefits of social media use include increased interactions with others, easily accessible and tailored information, social and emotional support, and public health surveillance.[74]

The nature of social media involvement by healthcare professionals can vary from direct engagement with patients for the purpose of communication to participation in online health networks dedicated to specific health and wellness issues.[70] Additionally, providers can guide patients and families to use social media during the illness trajectory in order to maximize the benefits of their use.[43,75] A systematic review of the effects of social media on patients and their relationships with healthcare professionals concluded that patient empowerment through the use of social media equalized the power imbalance between patient and healthcare professional, leading to increased quality of clinical decision-making.[76] Furthermore, social media interventions have shown some promise for cancer prevention and management by providing combinations of targeted, reliable information and social support.[77] Social media may also be a source of feedback to clinicians. For example, a study conducted in Japan in 2015 concentrated on Japanese men and women with a diagnosis of lung cancer in various stages.[78] Through analysis of 100 blog posts, the authors identified several themes. In general, the content focused on feelings of dissatisfaction and anxiety in cancer patients and their families, as well as on relationships with medical staff, insights not assessed in previous surveys. Most notably, researchers concluded that, when comparing the illness blog content to voluntary records from previous surveys conducted by the healthcare institution, the illness blog was predicted to be more representative of the patient's true thoughts and feelings.

Ethical Considerations

The adoption of social media use among healthcare professionals also carries ethical and professional implications.[79] Concerns have arisen about the blurring of professional and personal lines, inadvertent discussion of protected health information, financial conflicts of interest, advertising, and exploitation of patients. Various professional organizations have published recommendations to guide ethical social media use by healthcare practitioners.[79] Additionally, clinicians have a duty to counsel patients and families about the potential pitfalls of social media use, such as difficulty in establishing the reliability of information on social media as well as risks of confidentiality and privacy breach.[74] Organizations have an obligation to verify the accuracy of information presented on their sites and disclose conflicts of interest. Healthcare professionals have an obligation to maintain appropriate professional boundaries and protect patient privacy. Chretien and Kind[79] have published guidelines examining the ethical considerations for healthcare providers engaging with social media. The authors concluded that providers who successfully incorporate the use of social media while maintaining trust and integrity "will be poised to lead this social revolution in healthcare."[79(p. 1419)]

Conclusion

Social media provides many opportunities for individuals to connect with one another. These connections are important in leveraging social capital, especially during an illness experience. Current research supports the use of social media as a medium for public storytelling with many benefits to the ill person and family members. Benefits for the ill person include mustering social support, combating isolation, comparing and sharing information with others in similar circumstances, and providing a venue for self-expression. Family members may benefit in terms of facilitating sense-making, garnering social support, enhancing family communication, and, in the event of death, leaving a legacy.

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CHAPTER 67

Access to Pediatric Hospice and Palliative Care

Lisa C. Lindley and Jessica Keim-Malpass

Key Points

- Access to high-quality pediatric hospice and palliative care is becoming increasingly important as the prevalence of children with serious illness grows and the complexity of their health at end of life rises.
- State and federal policies have influenced access to care for children and families.
- Ongoing research has provided evidence on the distinctive profile of community-based pediatric hospice and palliative care providers.
- For many children and their families, community factors influence care utilized, whereas for other children it is their health conditions or complexity of their health.
- Nurses can advocate to expand access to hospice and palliative care for children.

Introduction

Access to high-quality pediatric hospice and palliative care is becoming increasingly important as the prevalence of children with serious illness grows and the complexity of their health at end of life rises.[1,2] The American Academy of Pediatrics[3] articulated its commitment to equitable access to pediatric hospice and palliative care, and the Standards of Practice for Pediatric Palliative Care and Hospice state the importance of accessible care for children and their families.[4] However, many children at end of life lack access to these care models, especially in the community. Statistics on the location of death suggest that home is the preferred place for children and families[5]; yet recent evidence suggests that fewer than a third of community-based hospice and palliative care providers deliver care for children, and less than 10% of children and their families utilize the services.[6,7]

Pediatric hospice and palliative care is end-of-life (EOL) care focused on enhancing the quality of end of life for the child and the family, preventing and/or minimizing suffering, optimizing function, and offering opportunities for personal and spiritual growth.[3,4] This care focuses on effective management of pain and other distressing symptoms, along with psychosocial and spiritual care. Hospice care is often distinguished from palliative care as EOL care provided in the last 6 months of life as certified by a physician or nurse practitioner. Community-based care is care accessed outside the inpatient setting and provided in the home, dedicated-hospice facility, or long-term care facility.[8]

This chapter addresses access to pediatric hospice and palliative care services in the community by examining the roles of healthcare policy, delivery of care, utilization of care, and quality of care. Research findings are used to illustrate the current evidence on access to care for children and their families. The chapter concludes with nursing recommendations on ways to improve access to pediatric hospice and palliative care.

Access Definition and Framework

Access to healthcare is a complex notion with varying definitions.[9] Access to pediatric hospice and palliative care is defined as EOL care that is available, accessible, accommodating, acceptable, and affordable for children with serious illnesses and their families. The conceptual framework created for this chapter was modified from the classic work of Aday and Andersen,[10] which conceptualizes access as a multidimensional process proceeding from health policy through the characteristics of the healthcare delivery system to the utilization of healthcare services and culminating in quality of care accessed (Figure 67.1).

Using this framework, access to healthcare is considered in a political context.[10] Federal and state laws guide access to services by defining financing and eligibility criteria. Next, the characteristics of the healthcare delivery system influence what care is available and accessible to patients.[10] There is a distinctive profile of providers who deliver care for children. Additionally, accessing care depends on whether or not the patient population utilizes healthcare.[10] For children at end of life, hospice and palliative care utilization is influenced by their health. Finally, the framework indicates that accessing care should result in quality care that is accommodating and acceptable to patients.[10] Accessed pediatric hospice and palliative care must be child- and family-centered care that reduces symptom burden and meets the needs of the child and family to their satisfaction. In summary, the framework provides a guide for this chapter on the dimensions of access to pediatric hospice and palliative care.

Health Policy

Due to reimbursement structures, delivery models, and financing, it is critical to first understand access to pediatric hospice and palliative care within the lens of health policy. An

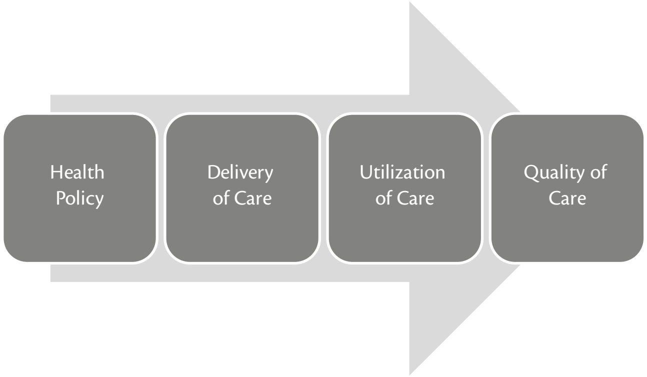

Figure 67.1 Framework of access to pediatric hospice and palliative care.

estimated 17,000 pediatric deaths each year are associated with chronic, complex conditions, and the vast majority of these children are enrolled in Medicaid due to their disability status, severity of disease, or overall level of functioning.[11] Additionally, private insurance does not usually cover in-home nursing care, so, in essence, Medicaid is the primary public financing structure for pediatric hospice care services.[12] Medicaid and most private insurers originally followed the Medicare hospice eligibility criteria that require a patient to be in the last 6 months of life and forgo any curative treatment. Families often had to choose between continuing curative therapies or receiving hospice care services. For many children with complex, chronic conditions, curative therapies include routine regimens such as antibiotics, antispasmodic drugs, and other therapeutics that promote optimal symptom management and functional status. In the 1990s and early 2000s, pediatric hospice care advocates recognized that making the decision to stop ongoing curative therapies to enroll in hospice care was a pervasive barrier to enrollment for many families.[13] Advocates argued that the either/or nature of the Medicaid hospice eligibility criteria was amenable to state-based policy because of the decentralization of Medicaid provision.

State Policies

Several states met the challenge of the early pediatric advocates and began to explore and test alternative pediatric hospice and palliative care models under their Medicaid programs. States such as Florida, California, and Massachusetts were early innovators in Medicaid hospice policy and developed programs and legislation to expand hospice enrollment for children with life-limiting conditions.[14] One way states are able to operationalize these programs and policies is through 1915 Medicaid waivers. These waivers allow states to offer benefits to home- and community-based services to promote children remaining in their home and community. Florida was among the first states to publicly finance concurrent curative and hospice care through a 1915 Medicaid waiver program, which waived many of the reimbursement rules.[15] Challenges to implementation in Florida in the early days of the program included identification of eligible children, workforce constraints, and billing complications.[15] Upon implementation of the Florida program, Medicaid was the primary funding source, covering 92% of the expenses of those enrolled.[15] As the program matured, there was a significant increase in the number of children enrolled, and families were highly satisfied with the care provided.[15]

California also was an early leader in alternative eligibility criteria and financing for pediatric hospice and palliative care. With the aid of their engaged pediatric hospice community, California advocates were successful in lobbying and enacting legislation such as the *Nick Snow Act*.[14] Nick Snow was a young man with a life-limiting condition who "failed" hospice twice (e.g., outlived his 6-month prognosis window) because his condition improved so much through the help of hospice. He was himself an advocate for expanded hospice access for children and adolescents.[13] California enacted concurrent care through the Nick Snow Act (Assembly Bill 1745) and later expanded their 1915 Medicaid waivers to incorporate this legislation.

In 2006, Massachusetts funded a Pediatric Palliative Care Network as a part of the overall state Healthcare Reform Act.[14] The Massachusetts Health Reform law included a one-time $800,000 financial appropriation for the training and implementation of expanded pediatric hospice access across the state, with the majority of money going directly to hospice contracts.[16] A key difference with the Massachusetts approach was that eligibility and financing were separate from Medicaid and did not include medications, durable medical equipment, home health aides, or other services that were covered through Medicaid.[12,16] In general, states that were early pediatric hospice and palliative care innovators established feasible models of care that loosened traditional hospice eligibility requirements and were well-received by the families of children who enrolled.[14]

Federal Policy

Recognizing the success of early state adopters of pediatric hospice and palliative care models, hospice advocates continued to garner bipartisan support for legislation on the federal level. Section 2302 of the Affordable Care Act (ACA) offered the first federal legislation aimed at modifying hospice eligibility criteria nationally for children enrolled in Medicaid or the Children's Health Insurance Plan (CHIP). Under Section 2302, children were eligible for concurrent curative therapies and hospice care upon the signing of the ACA on March 23, 2010.[17] The legislative intent of Section 2302 care included (1) expanded access for children with chronic, complex, life-limiting conditions; (2) enhanced child and family quality of life; and (3) earlier enrollment/longer length of stay in community-based hospice instead of frequent hospital admissions.[14]

Even though enactment of ACA Section 2302 made great efforts in uniformly offering access to pediatric hospice care across all states from the legislative context, there are several policy concerns remaining, including abilities of states to implement policies, solvency of state Medicaid budgets, limitation to Medicaid enrollees, lack of economic data suggesting overall return on investment, and shortage of trained pediatric hospice and palliative care workforce. For example, states that faced economic and budget concerns are less likely to implement Medicaid legislation (e.g., those facing Medicaid/CHIP budget crisis).[18] Additionally, there has been a dearth of economic and policy research focused on this provision and the cost-effectiveness of pediatric hospice as a whole, which impacts sustained policy engagement in the topic.[18] Finally, due to the continued political uncertainty of the ACA, many fear that uprooting this landmark legislation will adversely impact children with life-limiting conditions.

Delivery of Care

Who Delivers Care

Along with health policy, access to pediatric hospice and palliative care is influenced by the providers that deliver care for children and their families. Over the past decade, a distinctive profile of community-based, pediatric hospice and palliative care providers has emerged. Less than a third of all hospices provide care for children, and only a fraction of these have a special pediatric program.[19–21] Pediatric hospice providers are often small or medium sized and have been in operation for more than 8 years.[19,20,22,23] Most are nonprofit, nonaccredited organizations.[19,21–24] They are frequently free-standing and are not affiliated with a hospital or a home-health agency.[19,21–23,25] Pediatric hospices are often reimbursed by private insurance, followed by Medicaid and charity.[26] Most of their costs are in nursing labor, and their balance sheets typically indicate a positive trend with higher revenues than expenses.[26] Generally, pediatric providers are located in the South, and they commonly serve an urban community.[6,19,24,26–28]

In addition, our understanding of the nurse workforce within pediatric providers is expanding. Registered nurses (RNs) constitute more than three-quarters of the staff, with one full-time-equivalent (FTE) RN for every two patients in pediatric hospices.[23] Less than a quarter of organizations have advanced practice registered nurses on staff, such as nurse practitioners or clinical nurse specialists.[23,29–32] However, a majority of organizations have RNs on staff with a baccalaureate degree as the highest RN degree, while approximately 75% of nurses have a specialty certification.[19,23,30–34] Among pediatric hospices, RNs maintain one of the lowest caseloads while providing the most visits compared to other staff members.[22,24]

Factors that Influence the Delivery of Care

The characteristics of hospices influence the care delivered for children and their families. Emerging evidence has begun to identify key factors within the organization that may act as barriers or facilitators in the delivery of pediatric hospice and palliative care. Several of these characteristics have been investigated and are presented in detail here.

- *Company policies*: Some community-based hospice and palliative care providers do not deliver care for pediatric patients because of company policies. In a recent study, researchers explored hospice and palliative care delivered in rural Appalachia.[29] Through key informant interviews, they discovered that providers sometimes have specific corporate policies that do not allow them to deliver care for children and their families. Therefore, company policies may be a barrier to hospice and palliative care for children.
- *Clinical pediatric knowledge*: Community-based hospices commonly care for elderly patients and lack clinical knowledge of children, especially at end of life. In a study of North Carolina organizations, researchers identified important clinical barriers to providing care, such as a lack of pediatric-trained staff, lack of pediatrician consultation, and lack of pediatric pharmacy.[21] Although partnership with pediatricians and/or those skilled in providing pediatric EOL care has been suggested,[27] there are relatively few examples of partnerships or mentorship programs available. Thus, staff discomfort with providing care for children is a critical barrier to the provision of pediatric hospice and palliative care.
- *Educational environment*: The educational environment in the hospice has a positive impact on the delivery of pediatric care. Studies among providers that provide highly specialized pediatric hospice and palliative care show that the organization's teaching status, presence of advanced practice registered nurses, RN certification, and BSN education levels are important facilitators to the availability of services for children and their families; these factors include complementary and alternative therapies (CAM) and culturally sensitive care (i.e., interpreter services, materials translated, multilingual staff).[23,30,32] These organizations may encourage their staff and students to explore new methods of delivering care (e.g., CAM), and RNs with higher education levels may be more receptive to meeting the needs of diverse patient populations (e.g., translated materials). Studies show the importance of an organizational climate that supports nursing education in facilitating the delivery of care for children and their families.

In summary, a profile of the pediatric hospices suggests that providers have distinctive characteristics that influence the delivery of care for children and their families. Identifying the factors that influence the delivery of care suggests that there are barriers and facilitators to access, many of which are amenable to organizational change.

Utilization of Care

Who Utilizes Care

Another component in the access of pediatric hospice and palliative care is whether or not children and their families utilize these services at end of life. We are just beginning to understand who utilizes pediatric hospice and palliative care services. Although all age groups use hospice and palliative care, adolescents have the highest utilization.[24,27,35–37] Most of these children have serious health conditions (e.g., neuromuscular, congenital, cancer)[24,38,39] and cognitive impairments.[24] They often require the use of medical technology.[4,40] Almost 80% of children with serious health problems have a need for medical technology that includes feeding tubes, central lines, and tracheostomies.[40,41] These children also have high medication needs and average at least nine medications daily.[40] Finally, they suffer with multiple morbidities along with their primary diagnosis[7,24,42] and significant symptom burden.[25] At the end of life, these children typically experience uncontrolled pain, shortness of breath, and fatigue.[43]

There is also recent evidence on the hospice care received by these children. Studies have examined the care used by children and have found that it is often received in the home[4,25,44,45] and in an urban setting.[20,45] Children who enroll in hospice and palliative care have an average length of stay of between 1 and 24 days.[24,46] Almost all children utilize pain management and skilled nursing care.[24] Approximately half of children and families utilize pastoral and bereavement care, while less than a third use nonpharmacological pain management, intravenous therapy, wound care, and volunteer care.[24]

Factors that Influence the Utilization of Care

Physician prognosis,[47,48] community support,[48] financial hardship,[49] and the child's suffering[47] all contribute to the families' decision-making at the child's end of life. However, we are just beginning to understand the impact of a child's health on access to pediatric hospice and palliative care.[50] Listed here are some of the recent discoveries about health characteristics that influence utilization of care:

- *Cardiovascular conditions*: Children with cardiovascular conditions are significantly less likely to enroll and stay in hospice care compared to those without these conditions.[7,51]A possible explanation may be the complex care needs of children with cardiovascular conditions at end of life. Children with heart failure may have multiple providers from diverse subspecialties including cardiologists, pulmonologists, and interventional cardiologists. While these specialists may manage a portion of the care, they typically do not integrate care across the children's numerous providers. Thus, no one specialist may take the responsibility to make the referral to hospice care. Instead, families often become the primary caregivers, medical managers, and health systems navigators for their children. Thus, a cardiovascular condition is a barrier to utilizing hospice and palliative care for children and their families.
- *Cancer*: A cancer diagnosis has been linked to pediatric hospice and palliative care utilization.[39,46,52,53] One study found that 45% of children with cancer at end of life enrolled in hospice and palliative care.[54] This trend is pervasive among older adults as well[4] and is also supported by previous pediatric data, due in large part to the fact that malignancies are the leading nonaccidental cause of death in the pediatric population.[55]Aside from epidemiologic trends, it is likely that a cancer diagnosis offers more concrete ability to prognosticate compared to noncancer etiologies, which is imperative for hospice utilization.
- *Comorbidities*: Comorbidities have been examined in studies of utilization. The results of a recent analysis revealed that children with comorbidities were twice as likely to enroll in hospice compared to those without comorbidities.[7] Children with comorbidities may enroll in hospice and palliative care in order to manage pain and other complex symptoms at end of life. Children with comorbidities present with unique clinical challenges for EOL care in hospice and may benefit from hospice care. For example, enrolling in hospice may enable children to receive a thorough initial assessment, assessment of medications, and provision of other psychosocial services. It also suggests that hospice clinicians may be able to provide effective pain and symptom management or engage social work services or pastoral care. Comorbidities may act as a facilitator to hospice and palliative care utilization.

Special Populations

Utilization of pediatric hospice and palliative care has also been examined among special populations of children. Information on their unique patterns of utilization is described here.

Hispanic children: In the pediatric Hispanic population, community characteristics have been associated with hospice and palliative care utilization.[56,57] Approximately 11% of Hispanic children utilized hospice care at end of life, with the most common health condition being neurological and the least common congenital anomalies. Being home at end of life is important for Hispanic families.[38,57] Pediatric hospice and palliative care services located in the Hispanic neighborhood were positively related to hospice enrollment.[56] In addition, Hispanic children who resided in communities where they could receive palliative care early in the disease trajectory were more likely to utilize hospice care. This evidence points to the importance of community for Hispanic children and their families at end of life.

Adolescents: A profile of adolescent hospice and palliative care utilizers is also emerging, with a usual source of care playing an important role.[52,58–60] Among the 10% of adolescents who utilize hospice and palliative care, about half of them have a neurological diagnosis, with cancer and cardiovascular etiologies following in equal percentages. Almost half of these adolescents have comorbidities. An important predictor of hospice utilization among adolescents is having a usual source of care. Adolescents who were an established patient with an identified primary care provider were more likely to enroll in hospice and had longer length of stays compared to those adolescents without a usual source of care. A usual source of care may have long-term knowledge of the adolescent's health, which can assist the adolescent and the family in navigating the decision to use hospice. This evidence suggests that a usual source of care provider may enable adolescents to utilize pediatric hospice and palliative care at end of life.

Children with an intellectual disability: Children with an intellectual disability at end of life have complex health needs that influence their utilization of hospice and palliative care.[46,61] Studies have shown that children with an intellectual disability aged between 6 and 14 years most frequently use hospice and palliative care. Children with an intellectual disability at end of life experience epilepsy, suffer with multiple comorbidities, and have congenital anomalies. One recent study found that having an intellectual disability was negatively related to hospice enrollment and length of stay.[46] However, when children had both an intellectual disability and comorbidities, there was a positive association with enrolling in care. Therefore, the health complexity of children with an intellectual disability was a significant predictor of hospice and palliative care utilization.

These special populations' studies highlight the importance of understanding the unique features of children at end of life. For some children, community influences care utilized, whereas, for other children, it is their health conditions or the complexity of their health. These findings suggest that future research among these groups is clearly warranted to ensure access to high-quality pediatric hospice and palliative care for all children and their families.

Quality of Care

Pediatric palliative and hospice care must be viewed through the lens of equitable access to quality care for children and their families.[62] Patient- and family-centered care is a cornerstone of both pediatric palliative and hospice care that is often operationalized through care of siblings,[3] family-centered advance care planning/goals of care,[63,64] and bereavement support in the community.[65] Parent/caregiver and sibling involvement in care planning and various transitions in care have been the focus of recent research to date, but there is still a dearth of research focused on perspectives of the children or adolescents themselves. Lyon and colleagues[63,66,67] have led family-centered research endeavors involving advance care planning among children with HIV and cancer and have demonstrated that adolescents want to engage in care planning themselves and make decisions regarding their own care trajectories along with their family supports.

Many have expressed the recommendation of initiating palliative care as a standard of care early in the illness trajectory for certain diseases like cancer,[68,69] but those guidelines have not been uniformly accepted among all children with chronic, complex conditions and they are rarely implemented in practice. One reason that hospice and palliative care have not become routine among pediatric populations is the difficulty in demonstrating efficacy (symptom control, utilization) and cost-effectiveness. A recent systematic review assessed pediatric publications that focused on the end-of-life period and found only 15.4% assessed any patient-reported outcome and only 23.1% assessed a parent-reported outcome.[69] Much of what we know about the impact of accessing pediatric hospice care on quality outcomes has been based on Medicaid claims data.[35,36,51,53,59] Like palliative care outcomes, there have been very few opportunities to assess the impact of hospice on quality care outcomes and patient- or family-reported outcomes. It is imperative to elicit patient-reported outcomes from both children and adolescents themselves (when developmentally able) and from parents/caregivers if we are to better understand the impact palliative and hospice care have on symptom control and patient–family well-being from a large, generalizable population.

Even though there are very few patient- or family-reported outcomes among children who access either palliative care, hospice care, or both, several investigators have demonstrated that early initiation of palliative and/or hospice care for children with chronic, complex conditions yields high family satisfaction and acceptance.[15,16,70] From the policy perspective, it was feasible to implement the early state models of the hospice care provision that led to the concurrent care Section 2302 in the ACA, and families responded with high satisfaction.[13,16] Clinicians, researchers, and advocates must urge families to share their palliative or hospice care experience within their clinical and social networks and within larger media perspectives to more fully engage with policymakers. There should also be a sustained effort made to embed patient- and family-reported outcomes within electronic health records and utilization data to yield a more robust perspective on the potential impacts of early access and initiation of palliative and hospice care.

Recommendations for Nurses

How nurses can advocate for health policies that expand access to hospice and palliative care for children?

Listen and share patient stories (in a way that protects their identity). Humanizing patient's stories and experiences are a natural way that nurses can become involved in advocacy efforts. Nurses have many incredible stories to tell, and we are present with families during their most vulnerable moments. By speaking on behalf of patients or writing their stories in a meaningful way, nurses can add to the shared understanding of their experiences and struggles. As an example, the popular column, "Narrative Matters," in the journal *Health Affairs* gives clinicians the opportunity to share stories that have relevant and timely policy implications. It is often the case that politicians use these stories to advocate for certain health policies because stories provide an easier way of connecting to a cause. Statistics and numbers can highlight certain aspects, but the narrative-based approach to patients' stories allows the cause to have a face and greater meaning. Along with journals that have these types of columns, there are also opportunities to publish for newspapers, magazines, and online through blogs. Understanding how to advocate for individual patients and populations of interest, how to communicate about health policy, and how to apply advocacy to the role of the nurse needs to be introduced and taught as early as possible in schools of nursing, both theoretically and in clinical practice applications.

Use evidence-based practice and join pediatric practice committees that are committed to enhancing quality symptom management and family-centered end-of-life care. Some might not associate evidence-based practice with advocacy, but getting involved in practice committees and striving for the provision of the highest quality of nursing care is a natural fit for advocacy efforts. Always approaching evidence-based nursing as the gold standard in pediatric care delivery allows nurses to provide quality care while staying informed on issues specific to the populations of interest. By continuing to acquire this knowledge, nurses can effectively translate that knowledge and care to patients and families.

Network with those interested in pediatric palliative and hospice care through social media or nursing organizations. It has become easier to connect with other nurses, clinicians, and policy advocates through social media sites online such as Twitter, Instagram, and Facebook. Professional organizations often present a natural place to connect and learn about various advocacy efforts. The National Hospice and Palliative Care Organization has an advocacy section with current legislative agendas, and the Hospice and Palliative Nurses Association (HPNA) has numerous position statements easily found online through the organization's website. The American Academy of Hospice and Palliative Medicine (AAHPM) both includes policy goals and hosts an advocacy center on its website, which also includes connections to both federal and state policy initiatives, a quality workgroup, and a regulatory issues workgroup.[71] It is critical for nurses to see what is on the agenda in terms of policy and advocacy efforts and find a way to join a cause that works for them.[72] Additionally, there are opportunities to connect and learn through various health policy online courses and tools. For instance, the Oncology Nursing Society (ONS) has a long-standing online course entitled "Advocacy 101" so nurses can gain access to a basic understanding of the legislative process and health policy advocacy.[73] For family advocacy efforts to continue to be a component of nursing practice, a sustained integration of health policy and advocacy within nursing education is critical. Content about advocacy, legislation, health policy, and nursing needs to be tailored and introduced into the curricula for nursing students at every level, with various advanced applications included within graduate nursing requirements.

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SECTION VII

Special Issues for the Nurse in End-of-Life Care

CHAPTER 68

The Advanced Practice Registered Nurse

Clareen Wiencek and Alexander Wolf

Key Points

- Palliative care relieves suffering and improves quality of life for patients with serious or life-threatening illness and their families by offering symptom management, care coordination, and psychosocial and spiritual support from the time of diagnosis through the period of bereavement.
- Advanced practice registered nursing builds on the strong foundation of nursing practice by incorporating advanced knowledge and expertise in assessment, diagnosis, and management of persons with serious or life-limiting illness.
- The palliative care advanced practice registered nurse (APRN) demonstrates skilled communication and the ability to drive treatment plans based on the goals and preferences of the patient and family.
- The APRN Consensus Model, released in 2008, provides the regulatory model to standardize licensure, accreditation, certification, and education of all APRNs and enables APRNs to practice at their full scope, ensuring greater impact on patient, service, and system outcomes.
- Palliative care APRNs contribute to the financial viability of palliative care programs by providing cost-effective care and contributing to billing and reimbursement processes.

Introduction

Numerous initiatives and studies over the past two decades have identified the critical need for better care of persons with serious or life-threatening illness and for their families.[1–4] Palliative care has grown as a discipline in response to that critical need. Palliative care means patient- and family-centered care that optimizes quality of life by anticipating and treating suffering. Palliative care addresses the physical, emotional, social, and spiritual needs of patients and facilitates patient autonomy and choice whether or not the patient chooses to be treated simultaneously with life-prolonging therapies.[5]

Within a changing healthcare environment, advanced practice registered nurses (APRNs) have demonstrated their ability to adapt to the challenges posed by an aging population and by the increasing prevalence of chronic and life-limiting diseases concomitant with aging. Additionally, APRNs can help patients and families navigate an increasingly complex and fragmented healthcare system. A systematic review of APRN outcomes from 1990 to 2008 found that outcomes for APRNs are similar and in some cases better than those produced by physicians alone and that APRNs provide effective and high-quality patient care.[6] Similar findings were reported by Stanik-Hutt and colleagues in their 2013 systematic review of 11 aggregated outcomes of care provided by nurse practitioners when compared to physician care.[7]

Historical Perspective: APRN Practice and Regulation, the APRN Consensus Model, Academy of Medicine Reports

In the early twentieth century, nurses who had completed postgraduate coursework or who had extensive expertise in a particular clinical area were called *specialists*.[8] They were the predecessors of today's APRNs. In 1954, the first clinical nurse specialist (CNS) program was created at Rutgers University, and, in 1965, the first nurse practitioner (NP) program was established at the University of Colorado.[8,9] Initially, these roles were described as extending beyond the scope of nursing due to the inclusion of some practices and procedures from the discipline of medicine. It was not until the 1980s that the term "advanced practice" was adopted after growth within graduate nursing education allowed nurses to obtain advanced expertise within the field of nursing.[8] As defined by Hamric and colleagues in their textbook on the advanced practice role, APRNs have advanced knowledge and expertise in performing histories and physical examinations, ordering and interpreting diagnostic tests, and prescribing medications and other therapies appropriate for the management of particular symptoms or diseases.[9] But the rapid growth in APRN programs and practitioners during the 1980s led to concerns among the members of the National Council of State Boards of Nursing (NCSBN) about the lack of clear practice standards, inconsistency among state regulations that impacted APRN portability, and variation in educational programs.[10] These concerns led the NCSBN to develop and release the Consensus Model for APRN Regulation: Licensure, Accreditation, Certification, and Education (LACE) in 2008.[11] Since 2008, more than 44 nursing organizations have endorsed this regulatory model.[11] The LACE regulation is the vehicle responsible for the full implementation of the APRN Consensus Model, and representatives from each of the LACE constituencies continue to work toward this goal. As of 2017, many state boards of nursing have adopted portions of the Consensus Model, but there remains significant variation by state. The NCSBN's Campaign for Consensus website provides an interactive map that illustrates the adoption of the Consensus Model in each state.[11]

The APRN Consensus Model endorses a uniform model of regulation for the legal status of advanced practice registered nursing designed to align licensure, accreditation, certification, and education and to support a full scope of practice by all APRNs. It provides a definitive foundation for nurses who choose or plan to pursue advanced practice and has impact on licensing boards, certification corporations, schools of nursing, and accreditation entities.[10] The definition of each element of advanced practice is central to the Model. *Licensure* is the granting of authority to practice. *Accreditation* is the formal review and approval by a recognized agency of degree or certification in nursing. *Certification* is the formal recognition of the knowledge, skills, and experience identified by a professional association and with the intent to protect the consumer. Finally, *education* is the formal preparation in graduate-level or postgraduate certificate programs.

The APRN Consensus Model has two main components: APRN roles and population foci with additional APRN specialties, such as palliative care.[11] "Advanced practice registered nurse" or "APRN" is the new legal title and recognized credential to be used by any nurse licensed in any of these four roles: certified nurse practitioner (CNP), certified registered nurse anesthetist (CRNA), certified nurse-midwife (CNM), and clinical nurse specialist (CNS). The Model has helped to bring consistency to all four roles. Now, graduate-level education in an accredited program; completion of the core courses of advanced physiology, pharmacology, and assessment; and national certification in the provision of direct care to a patient population are required.[11]

The other main component of the APRN Consensus Model is the population of focus. The Model asserts that the APRN is educated in at least one of six population foci: family/individual across the life span, adult-gerontology, neonatal, pediatrics, women's health/gender-related, or psychiatric-mental health. An important element of the Model is that there must be congruence between the educational program and degree and the certification exam. Finally, the top tier of the Model refers to APRN specialties such as palliative care, oncology, and cardiology. While these specialties provide depth and reflect expertise in a specific area, these specialties have no prescribed educational criteria, no requirement for accredited certification or education, and do not require Board of Nursing regulation. Thus, APRNs may specialize in the care of these populations but cannot be licensed solely within these areas of specialty. The implication for hospice and palliative APRNs is that hospice and palliative care is no longer a primary practice but rather specialty only, necessitating preparation and certification in one of the six population foci.[11,12]

It is important that the palliative care APRN understands the basis for the APRN Consensus Model and the legislative and regulatory changes occurring at the state level. The overarching goal is to support the full scope of APRN practice and to improve access to APRN care by healthcare consumers, thus driving better outcomes for the entire population. Peer-reviewed research conducted over the past four decades has demonstrated the quality and safety of APRN practice,[6,7] and certifying agencies are working to ensure consumer protection through the adoption of the Model's regulatory language.[10] An individual state would demonstrate full implementation of the Model by passing these statutes: the APRN title, role delineation of the four roles, educational requirement at the master's or doctoral level, required certification, licensure in the APRN role, practice autonomy for the APRN, and full prescriptive authority. As work continues across the country toward full implementation of the Consensus Model, each APRN should stay abreast of the progress and refer to his or her state board of nursing for the most current regulations related to licensing and scope.[11,13] It is the APRN's responsibility to be familiar with relevant state law and to maintain a practice that is guided by legal, ethical, and professional practice standards. The 29th Annual Legislative Update on the licensing and regulation of APRN practice in all 50 states is an excellent resource.[13]

In addition to the APRN Consensus Model, two influential reports have been issued by the National Academy of Medicine (NAM), formerly known as the Institute of Medicine. The NAM's 2010 report *The Future of Nursing: Leading Change, Advancing Health* and the 2015 report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End-of-Life* are both of important historical note in the development and growth of the APRN role.[4,14]

NAM's *Future of Nursing* report strengthens the argument for the APRN role and the new regulatory structure to meet some of the challenges in the American healthcare system and includes four key messages relevant to advanced practice in all specialties and population foci:

1. Nurses should practice to the full extent of their education and training.
2. Nurses should achieve higher levels of education and training.
3. Nurses should be full partners with physicians and other health professionals in redesigning healthcare in the United States.
4. Effective workforce planning and policymaking require better data collection and improved information infrastructure.

Highly relevant to the practice of APRNs in hospice and palliative care, NAM's *Dying in America* provides a historical update on the challenges and progress in end-of-life (EOL) care over the past 20 years. Challenges include the increasing number of elderly; structural barriers to access, especially in marginalized groups; increasing cultural diversity in the country, which necessitates individualized care; and the imbalance between the palliative care workforce and need.[4] The NAM report outlines the three major barriers to changing the culture of care through education: curriculum deficits, lack of interprofessional education, and inattention to building communication skills. In the five major recommendations for change, NAM specifically recommends that all accrediting organizations require palliative care education for all specialties, that clinicians across every discipline should be competent in basic palliative care, and that nursing-, medical-, and social work-certifying bodies require competency in palliative care.[4] The findings and recommendations in this report by the National Academy of Medicine position all APRNs, especially hospice and palliative care APRNs, to drive solutions to fill the gaps in optimal care of those who are seriously or terminally ill.

There is evidence that the APRN Consensus Model, the NAM reports, and the efforts of nurses at the state level are having a positive impact on advanced practice. In 2016, 16 states adopted regulations to improve the practice environment for APRNs.[13] New Jersey now requires APRNs to pursue education in EOL care and includes APRNs in the definition of "physician" when completing physician orders for life-sustaining treatment (POLST) and includes APRNs in Hospice Licensing Standards. New York passed legislation that requires prescribing clinicians to complete an approved 3-hour course in pain management, palliative care, and addiction management within 1 year of obtaining a Drug Enforcement Administration registration. In addition, some states are reporting improved legal statutes related to APRN roles in pain management clinics.[13] Given the current opioid crisis, many states are passing statutes that regulate opioid prescribing and prescription monitoring programs, and APRNs should keep abreast of legislative actions in their individual state.[13]

In summary, the APRN Consensus Model is the accepted regulatory model that supports practice to the full extent of scope. When fully implemented, the Model will allow APRNs to meet provider shortages across the United States.[10,11] The overarching goals are to achieve uniformity in education and licensure, remove barriers to interstate endorsement, and promote common understanding of the APRN role for optimal impact on healthcare outcomes.[11] The intent of the Model is not to disenfranchise practicing APRNs, but, as graduate nursing programs, state boards of nursing, and certification corporations adjust to the Model's recommendations, some impact on existing programs and individual APRNs is expected to occur. Though grandfathering is a provision in the regulatory model and should exempt those already practicing within the state of their current license, it is recognized that the requirement for current, national certification in the role and population focus may impact some APRNs.[11] Of note, the APRN Consensus Model does not require or preclude the Doctorate of Nursing Practice (DNP) as an entry-level degree for APRNs, a point that has caused confusion for some in the APRN community.[11] The APRN should refer to the original position statement on the practice doctorate by the American Association of Colleges of Nursing.[15]

Developments in Palliative Care: National Consensus Project, National Quality Forum, and Joint Commission's Advanced Certification for Palliative Care

Three significant developments within the past decade reflect a period of growth and standardization in the discipline of palliative care and have implications for the hospice and palliative care APRN. First, the National Consensus Project (NCP) for Quality Palliative Care published the first edition of the *Clinical Practice Guidelines for Palliative Care* (NCP Guidelines) in 2004.[5] The NCP was originally a partnership of five national palliative care organizations: the American Academy of Hospice and Palliative Medicine (AAHPM), the Center to Advance Palliative Care (CAPC), the Hospice and Palliative Nurses Association (HPNA), the Last Acts Partnership, and the National Hospice and Palliative Care Organization (NHPCO). Several other organizations have since joined the NCP. The NCP Guidelines were intended to aid the development of palliative care programs, establish definitions of palliative care, set goals for access to quality palliative care, reduce variation, foster performance measurement and quality improvement, and promote continuity of palliative care across settings. The guidelines cover eight domains of palliative care: structure and process; physical aspects; psychological and psychiatric aspects; social aspects; spiritual, religious, and existential aspects; cultural aspects; care of the patient at the end of life; and ethical and legal aspects.[5] The third edition of the NCP Guidelines reflects current practice and is consistent with the two previous editions except that the title of Domain 7, "care of the patient at the end of life," was changed from "care of the imminently dying patient." The publication of the third edition reflects the maturation of the discipline, the changes in practice, the continued growth in the palliative care evidence base, and the impact of national seminal events such as the healthcare reform mandated in the Patient Protection and Affordable Care Act.[5] The essential underlying tenets found throughout the NCP Guidelines include patient- and family-centered care, comprehensive palliative care across care settings, early introduction of palliative care at time of diagnosis of serious illness, interdisciplinary teams, expertise in clinical and communication skills, relief of suffering, and focus on quality.[5] While the first three editions of the NCP Guidelines largely applied to hospice and specialty palliative care programs in hospitals, the fourth edition of the NCP Guidelines will have an increased focus on optimizing palliative care delivery across all healthcare settings and provided by all clinicians who care for patients with serious illnesses. The fourth edition of the NCP Guidelines is expected to be released in October 2018.[16]

While publication of the NCP Guidelines helped establish the definition and scope of palliative care, the National Quality Forum's National Framework and Preferred Practices for Palliative and Hospice Care Quality (NQF Preferred Practices) was also an essential step in the acceptance and implementation of those guidelines by the larger healthcare community.[17] The NQF is a nonprofit, public–private partnership focused on improving the quality of healthcare through the establishment of voluntary consensus standards. The NQF Preferred Practices are based on the NCP Guidelines and identify 38 preferred practices that will improve the quality of palliative and hospice care. Additionally, in 2012, the NQF endorsed 14 palliative care performance measures focused on symptom relief in acute illness and at the end of life; patient- and family-centered care that addresses psychosocial needs; and patient, caregiver, and family experiences of care. The NQF framework creates a quality measurement and reporting system that may be used to support improved reimbursement for palliative care services.[17] Taken together, the NCP Guidelines and the NQF Preferred Practices set the performance standards for new and existing palliative care programs.

The third development occurred in 2011, when the Joint Commission (TJC) launched advanced certification for palliative care.[18] This certification recognizes inpatient palliative care programs, in Joint Commission-accredited hospitals, that provide the full range of palliative care services and demonstrate exceptional patient- and family-centered care. More than 40 standards in program management, provision of care, information management, and performance improvement are included. TJC used the NCP Guidelines to develop this certification program, which can help APRNs and their teams to build the infrastructure needed for high-quality outcomes. This 2-year certification is also a recognition of the importance of palliative care to quality healthcare outcomes and is recognized as a major landmark for the specialty.[18]

There are several reasons why these national guidelines and TJC certification are indispensable to the professional practice of palliative care APRNs. First, the guidelines establish standards for program development and for clinical outcomes and serve as a nationally accepted benchmark of quality. Both Guidelines set the standard that palliative care teams must be interdisciplinary and that patients and families must have access to palliative care expertise 24 hours per day, 7 days per week. At the level of patient outcomes, the NQF advocates for screening and assessment of symptoms using standardized scales,[17] and the NCP Guidelines call for prompt response to psychological symptoms and regular documentation of response to treatment.[5]

Second, the NQF Preferred Practices and NCP Guidelines set standards for educational preparation for APRNs and members of the palliative care team.[5,17] APRNs are ideally suited to take a leadership role in providing experiences for all team members in the range of settings where patients receive care. The consensus guidelines should be used by graduate faculty to identify basic skills and knowledge that should be integrated into curricula and ensure that palliative care programs help advanced practice students develop specialist-level competency in all domains.[5]

An additional benefit to the use of the NCP Guidelines and NQF Preferred Practices and attainment of TJC advanced certification for palliative care is to conduct meaningful performance improvement activities using these national benchmarks. APRNs, as leaders on their teams, can use individual standards to form the core of performance improvement measures and plans, thereby elevating the quality of the structure, processes, and outcomes at the program and patient-family levels. Finally, the NCP Guidelines and the NQF Preferred Practices serve as useful frames for palliative care research. Any APRN conducting research should review the recommendations made in these publications. For example, the NCP Guidelines call for new research methods to overcome the shortcomings of randomized controlled trials in palliative care, demonstration projects and multicenter research to test some of palliative care's central tenets, and more detailed studies analyzing reasons for late referrals to hospice.[5] The NQF Preferred Practices identifies gaps in palliative care's knowledge base and has extensive notes on directions for research in each of the domains and in cross-domain issues.[17]

Competency, Education, and Certification

Competency

The APRN's expertise is built on the strong foundation of skills possessed by the generalist registered nurse. Compared with the generalist, the APRN has broader and deeper education and expertise in the areas of assessment, diagnosis, and treatment of disease as well as in prevention, health maintenance, and provision of comfort. Additionally, the APRN must hold a graduate degree in nursing, is nationally certified at the advanced practice level, and has a practice focused on care of patients and families.[9] The APRN is expected to engage in more complex problem-solving and has broader responsibility for patient care than the generalist nurse.

The HPNA, as the nursing association representing this specialty, has developed educational standards and competencies. The *Scope and Standards of Hospice and Palliative Nursing Practice, 5th edition*,[19] which includes standards for advanced practice, and the second edition of *Competencies for Advanced Practice Hospice and Palliative Care Nurses*[20] should be utilized by the APRN to assess personal congruence with these standards and by undergraduate and graduate nurse educators to assess program-level congruence. In the Scope and Standards, eight competencies are outlined for the generalist hospice and palliative nurse: clinical judgment, advocacy and ethics, professionalism, collaboration, systems thinking, cultural competence, facilitation of learning, and communication.[19] In the HPNA's companion publication on APRN competencies, the same eight competencies, plus a research competency, are defined and include details of additional criteria for the APRN's expanded scope of practice.[20] For example, both the generalist and APRN use the nursing process to address the multidimensional needs of patients and families, but the APRN assumes greater responsibility for the evaluation, communication, and documentation of care across healthcare settings.

Education

The NCP Guidelines call for improved education for all clinicians as a priority in palliative care. More than a decade ago, surveys confirmed that undergraduate and graduate nursing programs paid little attention to palliative care topics.[21] Recent reports from the National Academy of Medicine, the American Association of Colleges of Nursing, and HPNA indicate that there are significant gaps in education across disciplines and across undergraduate and graduate programs.[2,4,12] A seminal work by Ferrell and colleagues, in which 50 frequently used nursing textbooks were reviewed, found that only 2% of all pages had any EOL content.[22] In 2015, the National Academy of Medicine's report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,* highlighted the insufficient attention given to palliative care in nursing and medical education and recommended that palliative care training and education be considered as a licensing requirement across healthcare professions. Increased palliative care content has been endorsed by HPNA,[12] American Association of Colleges of Nursing (AACN),[2] and the NCSBN.[23] At the generalist level, palliative care content has already been successfully integrated into the National Council Licensure Exam for RNs (NCLEX-RN).[23] The most recent NCLEX-RN test blueprint includes content on EOL care, pharmacological and nonpharmacological approaches to pain management and comfort, advance directives, ethical practice, aging, and grief and loss.[23]

At the master's level, there has also been progress in palliative care programs. The first graduate nursing programs specifically designed for training palliative care APRNs were created in the 1990s. The first palliative care nursing master's program for clinical nurse specialists was established at the Breen School of Nursing of Ursuline College in Pepper Pike, Ohio, and for nurse practitioners at New York University College of Nursing.[24] The APRN is directed to the HPNA website for the current listing of graduate-level palliative care programs.[25] In 2004, the AACN endorsed the Position Statement on the Practice Doctorate in Nursing[15] recommending that all advanced practice graduate nursing programs transition to DNP programs by 2015. At this time, there is variability in the implementation of the Consensus Model, and, as stated previously, the DNP degree is not a required component of the APRN Consensus Model, and no state board of nursing is requiring the DNP for APRN licensure. However, DNP programs are growing at a considerable rate, with the promise that nurses with the practice doctorate will be able to drive urgently needed and meaningful change at the patient-family and system levels. Thus, the registered nurse or the APRN considering graduate education should refer to the AACN,[15,26] NCSBN,[11] or HPNA[25] sites for the most current recommendations regarding the required educational degree for advanced practice.

HPNA's standards for clinical education of hospice and palliative nurses provide guidance for registered nurses, APRNs and for educators.[27] The standards clearly define primary palliative nursing practice from specialty palliative practice. Because goal-directed care and relief from suffering in the face of serious or life-threatening illness are fundamental to nursing, all nurses practice aspects of primary palliative care. Specialty palliative nursing skills include knowledge of advanced pathophysiology, pain and symptom management, counseling, and communication skills; advanced knowledge about care of persons with serious or life-threatening illness and those who are imminently dying; management of complex pain and symptoms using complex regimens; utilization of expert communication skills; care coordination across settings; provision of psychosocial and emotional support to patients and families along the illness trajectory; and integration of cultural and spiritual dimensions of care into the treatment plan for all patients. In 2017, HPNA and the American Nurses Association issued a joint call to action that nurses need to lead and transform palliative care. The call for every nurse to provide primary palliative care for any patient with serious or life-limiting illness or injury is at the center of that call to action.[28]

The Clinical Education standards also define the categories of clinical experiences for APRNs: observership, preceptorship/practicum, internship, residency, fellowship, and immersion courses.[27] These experiences are defined as follows:

- *Observership*: The purpose is to introduce the nurse to palliative care, assumes the nurse is a novice, and may be a formal requirement or informal shadowing format.
- *Preceptorship/practicum*: These are academic clinical experiences required for degree completion and eligibility to sit for certification exams.
- *Internship*: A temporary position in which a nurse exchanges services for experience between the student and the organization, lasting for weeks to months.
- *Residency*: A period of advanced education and training that should be at least 12 months in length and normally follows graduation from a nursing program.
- *Fellowship*: A postgraduate experience that offers specialty role and skill development for the APRN. This is a structured program of didactic and clinical instruction directed toward specialty practice.
- *Immersion courses*: Typically 1- to 2-week intensive courses on palliative care with or without clinical content.

Continuing education is essential for the APRN to keep current in evidence-based practice that can be accomplished through self-study, clinical in-services, and professional conferences. APRNs should become active members of national, regional, and local professional organizations so they will have access to continuing education opportunities and provide mentorship to nonspecialists. In 1999, the AACN and the City of Hope National Medical Center formed the End-of-Life Nursing Education Consortium (ELNEC) to design a curriculum for teaching palliative care to nurses.[29] ELNEC has been a successful model for improving palliative and EOL education for nurses across all practice specialties including pediatrics, critical care, and geriatrics.[29,30] Such train-the-trainer programs can be particularly impactful because they have the potential to reach a much larger audience through the participants' efforts to replicate the training in other settings.

Certification: The Advanced Certified Hospice and Palliative Nurse

With the growth of APRN roles in hospice and palliative care, the National Board for Certification of Hospice and Palliative Nursing (NBCHPN), in partnership with the American Nurses Credentialing Center, initiated specialty certification for the APRN in 2001. The first examination was offered in 2002, and the NBCHPN became the full proprietor of the exam in 2005. There are several benefits to obtaining national certification as an advanced certified hospice and palliative nurse (ACHPN). Certification is a marker of professional competence and assures that care meets the established standards for quality and safety. In addition, certification validates the specialty, protects the consumer, and is necessary for APRN billing and reimbursement.[9,10]

The ACHPN exam tests knowledge in five domains of practice: clinical judgment; advocacy, ethics, and systems thinking; professionalism and research; collaboration, facilitation of learning, and communication; and cultural and spiritual competence. APRNs who wish to sit for the exam must meet eligibility criteria including graduate-level education and a minimum of 500 hours of clinical practice in palliative care.[31] The Core Curriculum for the Advanced Practice Hospice and Palliative Nurse, published in 2007 and revised in 2013, provides the foundation of knowledge for APRNs who practice palliative care and is an excellent resource for exam preparation.[31]

APRNs: Outcomes across Practice Settings

The positive outcomes of the care provided by APRNs across specialties and settings are well-substantiated.[6,7,32] Studies of the impact by nurse practitioners on quality and financial outcomes in the acute and critical care setting have shown a reduction in resource use and length of stay and no difference in 90-day survival or mortality when compared to care by resident teams.[33–35] Evidence shows that clinical nurse specialists drive cost-effective outcomes.[36]

Although palliative care as a specialty is relatively new and the number of certified APRNs in palliative care is less than those in primary or acute care, still, evidence shows their impact on positive patient- and program-level outcomes in acute and community settings. Additionally, APRNs have the opportunity to reduce the fragmentation of care that can occur during transitions from one care setting to another and for specific patient populations. The provision of expert symptom management by palliative care APRNs early in the course of cancer may improve quality of life and, in some cases, patient survival.[37,38] Home-based palliative care consults by nurse practitioners reduced total hospitalizations, total hospital days, and the probability of 30-day readmissions in a study of 369 persons with advanced complex illness.[39] Likewise, benefits of APRN-driven outcomes in pediatric populations have been shown.[40,41]

Billing and Reimbursement

APRN billing and reimbursement is an essential part of a palliative care program's business model, and it is easier to demonstrate and to understand the value that APRNs bring to a program through documentation of revenue generated by reimbursement from government and third-party payers. The following guidelines apply to reimbursement for APRN services provided in inpatient hospital settings, outpatient clinics, skilled nursing facilities, and at home. Hospice will be covered separately at the end of the section. Medicare, the federally administered health insurance available to those aged 65 years and older or who have end-stage renal disease or meet disability criteria, will be covered in some detail because it represents a large proportion of total reimbursement for hospital- and office-based care and because other third-party payers often follow Medicare's lead.[42]

Under the Omnibus Budget Reconciliation Acts of 1989 and 1990, APRNs were first granted limited ability to bill Medicare in rural areas and in skilled nursing facilities.[42] Prior to this legislation, APRNs could bill "incident to" physician services, but this applied only to patient encounters in which the physician provided direct personal supervision by being in the office suite at the time of the encounter and APRNs could not bill for new patients or new problems.[42] In the 1997 Balanced Budget Act, APRN billing was expanded significantly. APRNs in all geographic areas and practice sites were allowed to be reimbursed at 85% of the physician fee schedule under Medicare Part B.[42] "Incident to" billing continues to be an option, but applies to only a small number of encounters and is subject to numerous restrictions.[43] To qualify for Medicare reimbursement, APRNs must satisfy a variety of requirements. They must have a master's degree in nursing, advanced certification from a nationally recognized certification body, and a National Provider Identifier. The APRN must satisfy all of the state's practice requirements, including state RN and APRN licensure, and must document a collaborative arrangement with a physician even if the state does not have a collaborative practice law. The service being submitted for reimbursement must be a service for which a physician would be reimbursed, and the state must recognize the APRN's legal authority to perform that service. In addition, the practice cannot be owned by the hospital and the APRN's salary cannot be on the hospital nursing department's cost report because the hospital is reimbursed under Medicare Part A for those services.[42] The APRN who satisfies these requirements can bill Medicare Part B. These rules apply to both nurse practitioners and clinical nurse specialists, but clinical nurse specialists may have a more difficult time meeting the requirements either because of limits to or silence at the state level on their scope of practice.[42]

To be eligible for Medicare reimbursement, a service must be defined as a "physician service" and assigned a current procedural terminology (CPT) code to document the procedure done or the service provided.[42,43] The evaluation and management (E&M) CPT codes are the most frequently used in palliative care because, rather than describe procedures (which make up a small part of palliative care practice), they describe cognitive services such as history-taking, conducting the physical exam, decision-making, and counseling.[42] There are different sets of CPT codes for different practice settings, and each set comprises a range of numbers reflecting distinct levels of service. The level of service may be determined on the basis of either complexity or time. If greater than 50% of a clinician's time is spent in coordination and counseling, then the clinician may bill based on time. This can be an effective way to document the intensity of work in palliative care, especially if the physical exam is limited. For billing on the basis of complexity, the level of service is supported by documentation of the extent of the history, physical exam, decision-making, and counseling.[42]

Of particular import to palliative care APRNs, the Centers for Medicare and Medicaid Services now allow physicians and APRNs to bill specifically for time spent performing voluntary advance care planning.[44] Although there is reportedly no limitation on the number of times advance care planning can be reported and billed for a Medicare beneficiary within a specific time period, these services should be supported by documentation of changes to a beneficiary's health status or to their wishes for medical treatment and EOL care.[44]

A second set of codes for diagnoses is necessary to qualify a service for reimbursement. International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10) codes are used to describe the disease or symptom that is treated.[45] Examples include acute respiratory failure, pain, and nausea. Compared to previous revisions, however, the ICD-10 mandates greater specificity in the diagnosis and reporting of many conditions. It is important to note that a payer will not reimburse more than one clinician per day for the same indication. For example, a palliative care APRN who consults on a patient on a ventilator in an ICU and who helps manage the patient's dyspnea should avoid submitting the ICD-10 for acute respiratory failure because the critical care clinician or pulmonologist is likely to use that code. A better choice for the APRN in such a case would be to use the ICD-10 code for dyspnea. If two clinicians submit bills listing the same ICD-10 code on the same day, only the clinician whose bill is processed first will be reimbursed. It is possible to bill for concurrent care, even if the clinicians are from the same specialty, as long as each clinician is providing a different service and can bill for a different diagnosis.

In addition to Medicare reimbursement, APRNs may be eligible for reimbursement from other third-party payers including Medicaid, commercial insurers, and managed care organizations (MCOs).[42] Although many of the billing and reimbursement guidelines for Medicare are applicable to these other payers, the Medicaid plans have considerable state-to-state variation, and each commercial insurer and managed care plan has its own policies.[42] All APRNs should refer to their respective Board of Nursing for the current status of reimbursement for services.

The 2003 Medicare Modernization Act specifies that a nurse practitioner can directly bill Medicare Part B for services provided to hospice-enrolled patients, but only if she or he is the patient's attending, and only if she or he is not a paid or volunteer employee of the hospice. A nurse practitioner must be the patient's attending of record in order to bill, and, while nurse practitioners may complete hospice face-to-face encounters, they may not certify or recertify terminal illness or serve as physician replacements on hospice teams.[46,47] Nurse practitioners may order physical therapy, speech therapy, and occupational therapy but cannot order the initial referral to hospice.[46,47] Obviously, this statute remains a barrier to full scope of practice for the palliative APRN and contributes to fragmented transitions for patients and families.

Conclusion

The past decade has brought many changes for the APRN in palliative care. The growth in palliative care programs across the United States has provided more opportunities to provide care to patients with serious or life-threatening illnesses or injury across the age spectrum. Palliative care APRNs have the skills and knowledge to address healthcare challenges by contributing to interdisciplinary patient care; providing education to patients, families, and colleagues; serving as consultants; conducting research; and taking on leadership roles. In addition, reducing psychosocial and spiritual distress is a basic nursing role that palliative care APRNs fulfill by addressing symptoms and responding to suffering through compassionate presence.[48] The implementation of the APRN Consensus Model and responses to the National Academy of Medicine's recommendations are expected to promote and increase the optimal impact of advanced nursing practice. Each APRN must keep abreast of the regulatory changes and national and state progress during this time of transition as the APRN Consensus Model is fully implemented and federal healthcare reform continues. Fortunately, the NCP Guidelines, NQF Preferred Practices, and TJC Advanced Certification for Palliative Care are excellent resources for APRNs as they lead their palliative care programs toward optimal outcomes—for patients and their families, for palliative care programs, and for healthcare systems.

Case Study: A Patient in the Care of a Palliative Care APRN

PB is an 87-year-old Italian American woman, a retired schoolteacher, who had a medical history notable for Alzheimer's dementia, aortic stenosis, hypertension, and hypothyroidism. Although she was confused and demonstrated forgetfulness and word-finding difficulty, PB was participatory in activities of daily living and able to make her basic needs known.

Following her husband's death, PB moved in with her daughter. Over the following 2 months, PB experienced a rapid decline, punctuated by increased forgetfulness, confusion and agitation at night, and several falls. PB's daughter contacted her primary care physician, who recommended placement in an assisted living facility and a referral to a community-based palliative care program.

The palliative care APRN made a home visit and met with PB, her two children and their spouses, and one adult grandchild. When the APRN inquired about the family's knowledge of palliative care, the daughter stated it was like hospice and would keep her mother comfortable, but her son commented that they were not ready for this level of care as "it's not like she's dying or anything. Dad just died, I can't imagine losing mom, too." The APRN acknowledged the family's recent loss, allowed time for the family to ask questions, and learned more about PB. Due to concern for PB's safety, the APRN recommended a referral to the team's social worker. PB's family agreed that palliative care may help prevent trips to the hospital as well as to "plan for the future." The APRN reviewed PB's advance directive and noted that the patient had a signed durable do-not-resuscitate order. PB's family agreed that she would want to be kept free of pain if her heart or breathing stopped.

The team social worker made a visit the following week. With guidance from the social worker, PB's family was able to arrange for her to be placed in assisted living 6 weeks later, but PB had difficulty adjusting to another new living environment. The staff reported that PB was becoming severely confused at night, was occasionally combative, and was anxious and tearful during the day. The APRN made a visit to the facility and reviewed the patient's medications. A bedtime dose of melatonin 5 mg was added, and escitalopram 10 mg daily, which was escalated to 20 mg daily after several weeks. Additionally, the APRN contacted PB's family and her primary physician to discuss discontinuation of several potentially unnecessary medications, namely pantoprazole and atorvastatin. These medications were subsequently discontinued.

Over the next month, PB's anxiety and agitation gradually improved. During the following 6 months, PB was seen by the APRN every 6–8 weeks and was treated for several acute problems, including a urinary tract infection and volume overload. However, she did not require hospital transfer during that time. Her speech was notable for worsening confabulation and word-finding difficulty, and at times she required hand feeding. The APRN communicated with PB's family by phone to discuss her condition, and they expressed understanding that her dementia was progressing. They agreed that maintaining PB's comfort was the priority goal of treatment. With this goal in mind, the APRN recommended hospital transfers only if her comfort could not be maintained at the facility.

Two months later, PB was found unresponsive and dyspneic in her wheelchair. She was transferred by rescue squad to the emergency department, where she was found to be in acute hypoxic respiratory failure. A chest x-ray revealed a large right middle lobe infiltrate concerning for aspiration pneumonia. She was placed on high-flow oxygen and was started on a course of antibiotics.

The palliative care APRN was able to see PB the following morning. Although her work of breathing and oxygen requirement had improved, PB was obtunded and unable to participate in her care. PB became increasingly weak and deconditioned over the course of the week. The unit case manager recommended nursing facility placement for PB, but her family members strongly disagreed. PB's children felt that she had been through too much change and returning to a familiar setting would be most congruent with honoring her comfort. Since the APRN knew PB's current condition would exceed the level of care at the assisted living facility, hospice was recommended and family agreed. The APRN contacted the assisted living facility and confirmed that PB would be reaccepted at discharge with hospice support.

PB received hospice care at her assisted living facility for 1 month and continued to decline. She died 1 month later, with her family members present.

The case illustrates the significant impact that a palliative care APRN can have across the continuum of care when using expert communication skills and comprehensive approaches to symptom management. PB suffered unfortunate but common complications of Alzheimer's dementia, yet the APRN was able to build and maintain trust with her family, collaborate effectively with other team members to provide care across settings, cultivate shared decision-making, and honor the patient's preferences through the end of her life.

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CHAPTER 69

Self-Care

Kathy G. Kravits

Key Points

- Happiness is a key component of well-being.
- Well-being has a survival advantage.
- Well-being can be created through thoughtful and disciplined practice.

A Personal Perspective

Self-Care, a Journey of Discovery

> I was approximately 6 weeks out of high school when I started nursing school at a large public institution. My education was wonderful, but right from the beginning I was challenged by the suffering that I saw.
>
> At that time in our profession, we were counseled to remain "professional" when providing care, which meant not to display how we were affected by the suffering we saw. We were caught in a paradox consisting of expectations for caring and compassion for our patients while at the same time creating a façade of "professionalism" that denied our experience of suffering, especially of suffering we were helpless to stop.
>
> I graduated from school and spent the first 6 months as a registered nurse working on a general medical unit at the same facility where I trained. I chose to stay at that facility because I knew that I was committed to stopping at least some of the suffering I saw, and the patients who sought care there had very few resources to obtain relief.
>
> I was accepted into a critical care training program and worked in critical care for the first 15 years of my career. I thought the critical thinking and problem-solving would distract me from the suffering and help me to manage my increasing compassion fatigue. Wrong. The new layers of complexity in the actual caregiving only added to my distress. I became increasingly irritable and negative. My distress became unbearable. I was probably fully involved in burnout at this time, but did not recognize it. My distress became so unbearable that I changed jobs, thinking that that would help. Wrong. For the next 5 years, I changed jobs every year, never really improving. I descended more quickly with every job into burnout.
>
> My recovery did not start until I began to teach new critical care nurses about the biological basis of the stress response as proposed by Hans Selye.[1,2] Understanding that what I was experiencing was a normal biological response to exposure to stressors associated with professional caregiving including the suffering of others relieved me of the shame that I had been feeling. Shame associated with my belief that I was not good enough.
>
> I began to learn about self-care and how to create a fulfilling life. This process of self-discovery and healing is an ongoing one. I continue to evolve my understanding of what it means to care for myself. Every new practice that I implement in my life with self-compassion, self-reflection, and a holistic perspective helps me to grow to be a better person and a better nurse, less vulnerable to the challenges of being a compassionate caregiver.
>
> —*Kate Kravits*

Introduction

Palliative care providers, by the nature of their work, are exposed to patient care situations that require the expenditure of intense emotional energy (i.e., end of life, physical suffering, emotional distress, psychological pain, moral distress, etc.).[1,2] This chapter describes the vulnerabilities commonly associated with palliative care that put palliative care providers at risk for compassion fatigue and burnout. Evidence-based, self-care strategies that promote wellness are discussed, as is a process for developing a personalized wellness plan. The long-term, physiologic impact of body stressors are reviewed. Strategies for responding to stress are reframed as opportunities for gaining new awareness to promote resilience and allow for adaptation and growth. Well-being is defined, and the impact of well-being on quality of life and long-term survival is discussed.

Stress and Stressors

Hans Selye was one of the first researchers to study the response to stress in an organized and rigorous manner. He coined the term *general adaptation syndrome* (GAS) to describe the stages of the stress response.[1] In 1946, Selye not only described the GAS, but developed evidence to support the role of the endocrine system in the stress response and the role that stress plays in the development of chronic illnesses (i.e., cardiovascular disease, hypertension, diabetes, etc.).[2] Building on Selye's work, researchers have developed a detailed view of the stress response and have confirmed Selye's belief that the stress response can play a role in the development of chronic illness and organ dysfunction.[3] Individuals who either personally or professionally experience frequent, intense, and/or uninterrupted stressors must develop effective strategies for preventing and managing their exposure and response to those stressors in order to protect their long-term health and well-being.[4]

Biological Systems Supporting the Stress Response

Three important systems that mediate the stress response are the sympathetic adreno-medullary system (SAM), the hypothalamic-pituitary-adrenocortical axis (HPA), and the polyvagal system.[3]

These systems mediate the processes necessary for the individual to respond to threat.[5]

The SAM system consists of sympathetic nerve fibers that release norepinephrine (NE). NE, a neurotransmitter, increases respiratory rate, heart rate, and blood flow to voluntary muscles. Activation of the SAM system creates the earliest response to threat. It redistributes oxygen and glucose to the muscles and organs necessary for "fight or flight."[5]

The HPA is an endocrine system that functions during the stress response to promote the release of glucocorticoid. Glucocorticoid plays a significant role in metabolizing glucose from liver glycogen and in releasing the glucose into the bloodstream.[5]

The polyvagal theory suggests that the branches of the vagus nerve perform unique functions, including facilitating heart rate variability in response to changing environmental conditions and self-regulation.[6] The dorsal vagal complex (DVC) branch of the vagus nerve promotes survival by conserving resources through behavioral strategies such as immobilization and avoidance. Freezing and fainting may be triggered in response to actual or perceived loss of oxygen.[6] When people say, "I nearly passed out with fright," they may, in fact, be speaking the literal truth. In the face of extreme threat, when resources are insufficient to meet the threat, the body protects itself from suffering by freezing or fainting.

Initiation of the Stress Response

Sensory information is brought to the brain, and two pathways relay the sensory data to the limbic system and the prefrontal cortex for processing and action. The two pathways are known as the "quick" and "slow" paths. The "quick" path delivers sensory information to the limbic system, where threat is immediately determined and action taken, if necessary, through the activation of the SAM.[7] The "slow" path delivers sensory data to the prefrontal cortex and is designated as "slow" because, compared to the "quick" path, many more neurons are involved in the transfer of data and thus require a longer period of time to deliver information.[7] Cognitive processing of response strategies lags behind the more immediate responses of the sympathetic system.

Intentional choices to behave in a specific manner in the face of threat require activation of the prefrontal cortex. Deep breathing is an ideal behavior for retarding the sympathetic response through activation of the vagus nerve, allowing cognitive processing to take place. Many self-care practices include some form of breathing practice. Yoga and meditation are two examples.

Palliative Care and Emotional Labor

Palliative care, regardless of the discipline involved, relies on emotional labor to accomplish many of its goals. Unfortunately, emotional labor often is not recognized as a component of professional caregiving, nor is its impact acknowledged.[8,9] Emotional labor involves managing emotion and emotional displays in the professional caregiving environment. Emotional labor requires the use of personal energy and resources. It is an essential element of authentically attending to the patient, family, and caregiving team. Overuse of personal energy and resources in the pursuit of providing care without rest and renewal may be associated with role stress.[8]

Compassion Fatigue

Compassion, a vital component of emotional labor, is a feeling of profound sympathy that arises from witnessing the suffering of another and prompts the desire to intervene in that suffering.[10] Emotional labor requires that the professional healthcare provider be capable of experiencing compassion and use it in the context of delivering patient care.[8] *Compassion fatigue* describes a progressive decline in the ability to feel compassion and/or to act on those compassionate feelings.[11] The healthcare environment exposes providers to multiple sources of human suffering. Repeated, diverse, and intense exposures without reasonable opportunities for emotional recovery over time can lead to compassion fatigue.[12]

Compassion fatigue that occurs as a consequence of professional experiences can invade all domains of life, frequently impacting personal resources and relationships (i.e., spouses, family, friends etc.), making it increasingly more difficult to recover.[12] Presented in Table 69.1 are the signs and symptoms associated with compassion fatigue that are consistent with emotional exhaustion and the coping strategies used to manage the exhaustion.[12]

Table 69.1 Examples of signs and symptoms associated with compassion fatigue

Physical domain	Psychological/Emotional domain	Social/Relational domain	Spiritual domain	Professional practice domain
Alterations in sleep patterns	Irritability	Withdrawal from family activities	Loss of meaning and purpose	Avoidance
Changes in eating patterns	Episodes of tearfulness	Lack of interest in pleasurable activities	Hopelessness	Increased absenteeism
Unplanned fluctuations in weight	Impaired concentration	Conflict in personal relationships	Overwhelmed with uncertainty	Inability to meet obligations in a timely manner
Episodes of pain	Alterations in judgment	Isolation		Disengagement
Decrease in self-care activities	Emotional emptiness			Errors and other safety violations
Substance use	Feeling removed from self			Conflict in work relationships
	Feelings of helplessness			Frequent changing jobs

Secondary Traumatic Stress Symptoms

There has been a great deal of confusion in the literature about *secondary traumatic stress symptoms* and whether this is the same syndrome as compassion fatigue. The evidence suggests that they are different experiences with different etiologies that may present with some of the same signs and symptoms.[13] Secondary traumatic stress symptoms occur in the context of an individual who has experienced adversity historically and is traumatized by experiences in the present that are similar enough to the original experience(s) to reactivate the feelings and memories associated with the original trauma.[13]

The coping behaviors and associated resultant signs of individuals who are experiencing secondary traumatic stress symptoms may overlap with some of the signs of compassion fatigue. Healthcare providers may suffer from both syndromes. Management is different for secondary traumatic stress symptoms and requires professional assistance. If proactive, positive self-care measures fail to bring relief, working with a mental health professional may be appropriate to create a successful remedy.

Burnout

Burnout has been investigated for more than 20 years. It is considered an occupational risk for individuals working in human service professions including healthcare. Maslach is one of the seminal researchers in the area of burnout and one of the creators of the most frequently used instrument for measuring it, the Maslach Burnout Inventory.[14]

Maslach defines burnout as "a psychological syndrome occurring in response to prolonged interpersonal stressors at work."[14] In the original conceptualization of burnout by Maslach and her colleagues, burnout included three subcategories: emotional exhaustion, depersonalization, and personal accomplishment. The subcategories have been reconsidered to be emotional exhaustion, cynicism, and inefficacy. Replacement of depersonalization with cynicism acknowledges the influence of negative attitude on the development of burnout. Inefficacy emphasizes the impact of feelings of helplessness on the development of burnout.[14,15]

In recent years, *engagement* has emerged as an important concept with regard to work environments. Engagement is the subjective experience of being fully absorbed. While engagement is defined in different ways, researchers agree that engagement is an important, positive, accomplishment-affirming factor in the workplace. The evidence indicates that engagement is composed of the qualities of vigor, dedication, and absorption, and it serves as a counterbalance to the circumstances that promote burnout.[16]

Engagement is influenced by both personal and contextual factors.[16] There is evidence to suggest that engagement improves well-being and health.[16,17] Gander and colleagues conducted a randomized, placebo-controlled online trial of interventions addressing pleasure, engagement, meaning, positive relationships, and accomplishment as strategies to increase well-being and reduce depressive symptoms.[17] The results of this study of 702 individuals suggest that engagement has a beneficial effect on well-being and depressive symptoms. However, the degree of distress present when enrolling in the study may have influenced the degree of response found.

Gander and colleagues developed an intervention that relied on attending to personal experiences that meet the definition of engagement.[17] The intervention instructed: "Remember three things you have experienced today where your attention was particularly focused and you were not aware of your surroundings. Write these three things down and describe how you felt." This intervention identifies and describes both the circumstances of the experience and the feelings associated with those circumstances, which are then documented, thus creating a journal of "engaged" moments. The material is then available for intentional choice as the individual works to create a more enriched life and better well-being.

Antecedents of Burnout and Compassion Fatigue for Palliative Care Providers

The work environment is the context within which burnout and compassion fatigue most commonly occur. Some of the personal vulnerabilities identified in the literature include genetic predispositions, transgenerational histories of trauma, insecure attachment, childhood adversity, historical trauma, maladaptive coping such as substance abuse, and personal losses including divorce and death.[18–20]

There is well-documented evidence of vulnerabilities that predispose a palliative care provider to develop burnout or compassion fatigue. Many of the risk factors are associated with providing service to patients at end of life. They include the providers' feelings of helplessness that come with the inability to relieve the suffering of their patients, psychological challenges that are part of assisting a patient's adaptation to catastrophic illness, and navigating with the patient those losses that are part of the illness and treatment experience, including the loss of meaning and purpose.[20,21]

Professional expectations and behaviors that may contribute to the development of these syndromes include overinvolvement (blurry professional boundaries), unrealistic personal expectations of the caregiving experience, attempting to meet personal needs through work, and work not a fit for the personality.[10] As noted in Box 69.1, there are five organizational characteristics commonly identified with increasing the risk of burnout and compassion fatigue.[14]

Organizations can create systems and structures that intensify the potential for staff to develop compassion fatigue. Rotating shifts is one of the factors identified in many work environments that contributes to the risk of burnout and compassion fatigue and diminishes workplace safety.[16] Workloads perceived by staff as impossible to manage and lack of management support are organizational factors that also contribute to compassion fatigue and burnout.[14] Workplaces that successfully construct management structures that incorporate, in a meaningful manner, employee contributions to the development of work routines reduce rates of burnout and compassion fatigue within their organization.[10,22]

Consequences of Burnout and Compassion Fatigue

Burnout and compassion fatigue can be associated with negative interpersonal, physical, and professional consequences.[14] Some of the consequences are declining work performance, safety violations, errors in judgment, inability to concentrate, disruption of relationships, and diminished participation in recreational activities. Additional signs and symptoms associated with burnout and compassion fatigue are noted in Table 69.1.

Box 69.1 Sample Wellness Plan

Intention Statement(s)

An intention statement is an "I" statement phrased in the present tense using action-oriented verbs. It represents an action, pattern of behavior, and/or thought process that the individual intends to incorporate into his or her life. For example:

1. I am healthy and energetic.
2. I practice random acts of kindness.
3. I count my blessings daily.

Action Matrix

Domains	Action/ Frequency	Resources	Re-evaluation
Positive emotion	Daily counting of blessings	None	Weekly review
Engagement	Weave with absorption and passion	Weaving materials	At the end of each session
Meaning	Practice daily meditation	None	Did I practice?
Positive relationships	Make cookies for the toddlers in the neighborhood	Cookie mix	Ongoing contact with the family
Accomplishments	See patients one day a week	Group practice	Full schedule

Qualities that Protect the Palliative Care Provider from Burnout and Compassion Fatigue

There are individual and organizational qualities that may decrease the likelihood that the individual will develop burnout and compassion fatigue. Individual qualities include feelings of self-efficacy, optimism (ability to frame experience in terms of opportunity and learning), hardiness (triumph of hope over experience), and resiliency (recognition of internal and external resources).[22,23] These qualities provide an emotional foundation that encourages the individual to reframe challenging experiences and to learn new, adaptive strategies for managing these challenges in the future.[2] Organizational factors that promote engagement and inhibit the development of burnout and compassion fatigue are outlined in Table 69.2. Each of the qualities protects feelings of self-efficacy and communicates that the organization values the healthcare provider.[14]

Creating Well-Being through Self-Care

Well-Being

Well-being is a model for creating a fulfilling life.[23] It is composed of five aspects of life: positive emotion (comprised of life satisfaction), engagement (vigor and absorption); meaning ("belonging to and serving something larger than yourself"[25]), positive relationships (well-being occurs in the context of relationship), and accomplishment (success not for gain but for the pursuit of a goal).[23–26] Cross-culturally defined personal qualities associated with well-being include kindness, fairness, authenticity, gratitude, and open-mindedness.[24] Well-being has been shown to be associated with improved physical health as well as improved mood and feelings of happiness.[23–26]

Table 69.2 Remedies

Individual	Organizational
Change work patterns	Improved civility
Alter coping skills	Job crafting
Increase social support	Workload management
Relaxation strategies	Employee recognition
Promoting fitness	
Self-reflection	

Source: From Reference 15.

Self-Care

Effective self-care creates well-being.[18] Mill, Wand, and Fraser conducted a self-care survey of 372 palliative care practitioners including physicians and nurses. They reported that "most respondents regarded self-care as very important (86%) and less than half (39%) had received training in self-care. Self-care plans had been used by a small proportion of respondents (6%), and over two-thirds (70%) would consider using self-care plans if training could be provided."[18] These findings highlight that while the desire to practice positive self-care exists, there is a demonstrable lack of ongoing education and follow-up available for many healthcare providers. Dorociak and colleagues identified professional support, professional development, life balance, cognitive awareness, and daily balance as some of the key categories for effective professional self-care strategies.[24]

There are barriers to self-care that can be seen in a wide range of populations. Some of the barriers described in the literature are low levels of self-efficacy, beliefs that self-care can't be sustained or won't work, lack of knowledge, financial constraints, and lack of social support.[27,28]

Elements of Self-Care

Positive, proactive self-care requires both "a will and a proper way."[25] Positive, proactive self-care also requires an expectation that things can get better. It is important that self-care is attached to meaning-based activities and it requires active self-discipline.[25] The process for creating positive, proactive self-care strategies includes self-reflection, positive self-efficacy, body monitoring, planning, and action.[28]

Self-Reflection

Self-reflection examines expectations for positive outcomes. The self-reflection should be conducted with compassion and should be nonjudgmental. The self-reflection is beneficial when it includes past failures as well as past successes.[29] Making use of experiences arising from less than desirable situations requires that the individual reframe them from negative experiences into learning opportunities.

Reframing negative experiences is easy when it is started by asking oneself, "What did I learn from this situation?" This question refocuses the self-reflection from a negative self-judgment expressed in negative self-talk like, "I am so stupid" to an analysis of the experience as a new opportunity for learning new lessons and creating new, more effective coping strategies. These learning opportunities have the ability to fuel adaptation and growth.[29,30]

Self-Efficacy

Positive self-efficacy is an individual's knowledge that he or she is capable. Without an individual's believing that he or she can be the agent of success and growth, there will be no positive self-care.[23] Believing in oneself is sometimes extremely hard to do. Martin Seligman, in his book, *Flourish,*[23] offers an exercise for developing a broader and more enduring belief that one is capable. He suggests the following steps: take a moment in a peaceful, quiet environment and reflect on one's strengths. Then, make a list of those strengths and the situations in which they most commonly manifest. This can be done as a written list, but may be done through the use of a more nonverbal medium such as visual art-making. Then, select one strength and imagine how that strength could be used differently. Make a plan for using that strength in a new way, write the plan down, and commit to a timeline for doing it. Once the plan has been implemented, reflect on it. Remember to reframe and recreate if the results were less than desirable and do it again. He counsels that sometimes a single attempt is not enough. Regardless of one attempt or several, this exercise takes abilities that are often unappreciated and brings them to conscious awareness, employing them in new and creative ways that cement the belief in one's self-efficacy.[29]

Body Monitoring

Body monitoring, in its most basic sense, is regular assessment of bodily processes through intentional redirection of attention to the body, without the use of external sensors and/or surveillance using sensors (i.e., blood pressure monitors, blood glucose monitors, etc.). Body monitoring is frequently used as one element of self-care strategies to manage chronic illnesses such as heart failure and diabetes.[31–33] It is also a valuable process to use when needing to assess an emotional response as expressed by bodily sensations and symptoms.[30,34] Successful positive, proactive self-care requires that ongoing monitoring of bodily responses be carried out and used to provide feedback that supports the self-care plan and/or modification of it.

Bodily sensations are frequently discounted as valuable data about our well-being, and yet our most powerful forms of communication are frequently nonverbal. Ignoring bodily sensations is learned through life experience, especially when it is important not to feel an emotional response.[30] Healthcare providers are particularly vulnerable to this because regardless of how they "feel" when they are in professional situations, they learn to ignore their feelings in service of their brain in order to provide safe and effective care. It is important to reacquaint ourselves with our body's voice in order to achieve well-being.

Begin to familiarize yourself with your body by placing yourself in a quiet, restful environment without external distractions. Pay attention to your breath, progressively allowing it to become deeper and slower. As your breath slows, beginning at your toes, notice which muscles feel relaxed and which feel tense. Gradually move your attention up your body, noticing how the right and left sides of your body feel. Do they feel the same? Where is the tension in your body held? Is there any tension? Continue this surveillance for a minimum of 2–3 minutes and make a note of your bodily sensations and any feelings that go with them. Continue this as a regular nightly ritual. Over time, your bodily sensation will communicate how you feel on a subtle level, and you will begin to be able to use this information to create new strategies for well-being. An excellent resource for learning more about how to communicate with your body is *Sensorimotor Psychotherapy: Interventions for Trauma and Attachment,* written by Ogden and Fisher.[33]

Self-Care Planning

Writing plans down increases the likelihood that they will be accomplished.[34] For example, writing down a daily schedule for exercise reinforces the intent to exercise and results in a greater likelihood that exercise will take place. Wellness plans may take any form that is useful. Regardless of format, two essential elements of a wellness plan help to establish expectations and to create a comprehensive plan of action. They are a statement of intention and a matrix of actions organized by areas of well-being. Box 69.1 presents Sample Wellness Plan, as a suggested model for creating a comprehensive self-care plan.

An *intention statement* is an "I" statement phrased in the present tense using action-oriented verbs. It represents an action, pattern of behavior, or thought process that the individual intends to incorporate into his or her life. The intention statement should be phrased as if it were already true. By doing this, the intention is taken in and stored as if it were already the manner in which the individual behaves. It is recommended that a maximum of three intentions are documented in the wellness plan. Any more may dilute focus and are more challenging to track. Examples of several intention statements are presented in Box 69.1, Sample Wellness Plan.

A comprehensive well-being plan is created by identifying behaviors that will support the intention statement(s) and that address creating positive emotions, engagement, meaning, positive relationships, and accomplishments.

Positive Emotions

Creating positive emotions can be accomplished many different ways. One way is described by Seligman (2011) as "Imagining a best possible self."[23] Every evening before retiring, write down a minimum of three things that went well during the course of the day. On the same page, write down an affirmation (positive intention statement) that supports some aspect of those positive occurrences. Over time, the number of things that go well in the course of a

Box 69.2 Organizational Risk Factors for the Development of Burnout

- Workload
- Control
- Reward
- Community
- Fairness
- Values

Source: From Reference 15.

day will grow. Alternatively, one may become more proficient at noticing the positives as they happen.

Expressing gratitude is very effective in helping to create positive emotions. Once again, writing helps to make the experience of gratitude more lasting, and it allows the gratitude to be shared. Write a letter of gratitude. Mail it or not, but by writing it the experience has a profound impact.[23] A woman once reported that she began to work on her experience of gratitude by counting her blessings while walking her dog. In the beginning, she would run out of blessings before she left her yard. At the time she was describing her experience, her walk had grown to 90 minutes, and she was still counting blessings after returning home. Her experience is an example of the maxim, "We grow that to which we pay attention." The other benefit was that she was able to monitor her progress toward well-being by counting her blessings while performing a specific activity.

Performing an act of kindness can increase positive feelings. Seligman (2011) describes an exercise in his book, *Flourish,* designed to expose the impact of random acts of kindness on mood. He recommends identifying one unexpected kind thing to do and do it. He then suggests, "Notice how you feel."[23]

Meaning

Meaning is defined by Martin Seligman in his book, *Flourish*, as "belonging to and serving something bigger than the self."[23] Meaning is not entirely a subjective experience of the individual, but may be specific to the individual. Cultural biases and values may define what is meaningful for a group or society and therefore influence individuals' understanding of meaning. Meaning is an autonomous element of well-being and is measured separately from positive emotions, engagement, positive relationships, and accomplishments.[23]

Gander and colleagues used an intervention in their 2016 study to increase awareness of meaningful experiences. The intervention was framed in a manner similar to others in that the study used the following injunction, "Remember three things you have experienced today that were personally significant and meaningful. Write these three things down and describe how you felt."[17] Being able to identify what is truly meaningful to an individual promotes effective coping in times of uncertainty and bolsters feelings of hopefulness.[17]

Positive Relationships

Positive relationships have been identified as an important adult developmental milestone. In the pursuit of well-being, positive relationships and the ability to sustain one is a key indicator of good health, optimism, and well-being.[30] Comfort, safety, and support can occur in the context of a positive relationship. As with many of the other elements, it is important to be aware of your relationships and whether your partner, family, and community help you achieve the things that are most meaningful.

Accomplishments

This chapter has already addressed self-efficacy. A related but separate construct is accomplishment. Recognition of accomplishment helps to reinforce self-efficacy and has value in its own right.[24] Awareness of accomplishment is important. Using the same model as with the other elements, "Remember three things you have experienced today where you were successful or where you had the impression that you did something really well. Write these three things down and describe how you felt."[24]

Conclusion

Well-being protects physical and emotional health.[23] Following the road map laid out by Seligman enhances well-being. Practice gratitude, count your blessings, take action, and believe better things are on their way.

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CHAPTER 70

Ethical Considerations in Palliative Care

Maryjo Prince-Paul and Barbara J. Daly

Key Points

- What constitutes "extraordinary care" will be almost entirely contingent on the values and clinical situation of the patient.
- Effective palliative care that rests on a sound ethical foundation requires ongoing discussions about patient and family values and preferences.
- Decisions regarding ethical dilemmas and the choices that are necessary require thoughtful discussion and critical communication skills.
- The ethical duties of all healthcare providers include the obligation to respect diversity in the views of colleagues as well as patients.
- All healthcare professionals have the right to and responsibility for maintaining their own ethical integrity.

Ethics and Moral Reasoning

Ethics, broadly defined, is the branch of philosophy that is concerned with the study of human conduct, with the rational analysis of how human beings ought to behave, and the methods by which we can identify good and evil, right and wrong.[1] In contrast, the term "morality" is conventionally used to refer to accepted and rational codes of conduct governing behavior, aimed to promote good and minimize evil.[2] As can be seen, these terms are closely related and are often used interchangeably.

Much of this text is concerned with the practical sense of nursing—that is, the application of natural and behavioral sciences in designing and implementing effective processes of care. This chapter will address what Bishop and Scudder refer to as the "primary sense of nursing practice," the moral sense.[3] The focus will be on the most common issues faced by nurses in palliative care. Our objective is to prepare the nurse for identifying, addressing, and resolving the complex questions that arise in caring for individuals and families facing life-limiting illnesses.

In confronting ethical questions, nurses may experience varying levels of moral quandaries. Given the complexity of the healthcare system and individual patient situations, nurses often are uncertain about the right or most ethically sound action. *Moral uncertainty* can produce discomfort, but it is the hallmark of a morally sensitive agent. It signals doubt or confusion about values or rules, but it can usually be resolved with careful analysis, as we will illustrate with case studies. In contrast to uncertainty, *moral dilemmas* are more troublesome and occur when the nurse finds her- or himself in a situation with conflicting demands or one in which every possible action seems to involve violating an ethical duty. Dilemmas may be associated with significant stress and anxiety; resolution may require assistance of others to sort through the conflicts involved. *Moral distress* is the most damaging state and occurs when the nurse perceives a moral duty but is unable, often because of external constraints, to fulfill that duty. Persistent moral distress can lead to disillusionment, moral apathy, and eventual resignation.

Dealing with ethical questions before moral distress occurs requires knowledge and skill in ethical reasoning. While thorough exploration of ethical theories is beyond the scope of this chapter, a brief review of the major theories that are the basis for the commonly accepted principles of autonomy, beneficence, nonmaleficence, and justice will be helpful. Following this review, specific issues that the palliative care nurse is likely to face will be explored, with particular attention paid to analysis of the problems.

Moral Reasoning

As mentioned, ethics as a discipline has its roots in philosophy. There are many ethical theories that have been developed over the years, each with its own justification. The best known of these are deontological theories and consequentialist theories. *Consequentialist theories* evaluate the justification for actions by examining consequences. The action that produces the best consequences for the greatest number is the preferred or "right" action. *Deontological theories*, in contrast, argue that actions are right or wrong according to their adherence to duties and obligations, not by virtue of the consequences of the actions. Both types of theories generate principles, such as autonomy (the right of self-determination), beneficence (the duty to promote good), and nonmaleficence (the duty to do no harm). From principles, in turn, more specific moral rules can be derived. For example, the general duty to respect autonomy and the right of self-determination is the basis of the specific rule that we obtain informed consent before interventions.

Both deontological and consequentialist theories are forms of a *principlist approach* to ethics. Principlist approaches, although they may rest on differing theoretical premises, all use general and relatively universal principles as the central tool for ethical analysis. Universal principles play a key role in developing mature ethical agency, provide reliable rules of thumb for responding quickly in real-life dilemmas, and reflect the considered wisdom of decades of philosophical analysis. Nevertheless, abstract and somewhat rigid principles can be insensitive to the nuances of specific clinical situations and conflict with the deep intuitions of experienced clinicians. More recently, appreciation for the importance of context has grown.

Feminist ethics, an *ethic of care*, and *narrative ethics* are relatively new approaches to ethical analysis. The development of feminist ethics, an outgrowth of the feminist movement, was encouraged by the work of Carol Gilligan, who studied moral reasoning in children and found that boys typically relied on a rule-oriented, justice-based approach, while girls tended to analyze situations in terms of relationships and context, seeking resolution in the details of the story or narrative.[4] Consistent with Gilligan's work, caring as a basis for ethics rests on the assumption that morality is rooted in human relationships and feelings. Nel Nodding, recognized as the originator of this theory, argues that morality must stem from the caring instinct and that the ethical ideal is located in the reciprocal caring relationship between and among persons.[5]

Narrative ethics uses the stories of patients and health professionals as the unit of analysis. In seeking understanding of ethical dilemmas from a narrative perspective, the elements of the situation are viewed as components of the story, and aspects such as the relation among participants, predominant voices, intentions of the actors, and consideration of whose voices are heard and not heard are central to developing understanding of the ethical dimensions.[6] As with the ethic of care and feminist ethics, understanding the relationships among all participants, the meaning of what is stated and unstated, and the motives of all involved is key to the evaluation of how best to respond in ethical dilemmas. Sara Fry has argued that the traditional approach to medical ethics, which centers on application of objective principles and simply evaluating which principle takes priority, is no longer adequate as a foundation for nursing ethics.[7] She points out that caring, as an ideal, is a more comprehensive basis for the traditional values of autonomy and doing good for patients. Rather than relying on moral theory, Fry suggests that nursing ethics rests on a moral view of persons. Thus, in the discussion that follows, we will attempt to evaluate issues and illustrative cases with reference to the usual moral principles, but will also consider the moral obligations that may stem from the caring relationship that nurses have with their patients.

Regardless of the theoretical underpinnings of ethical analysis, the nurse who identifies ethical issues or questions will need to use a systematic process to examine the situation and reach a decision about what action to take. There are many suggested models for analyzing ethical dilemmas, and any thoughtful, deliberative process can be helpful. One approach that is similar to the problem-solving steps most nurses have learned is illustrated in Box 70.1. The process begins with identifying the issue or question; this step helps to focus the ethical issue, clarify what aspect of a complex patient care situation is raising concerns, and differentiate the ethical dilemma from clinical problems. The second step, a review of facts and assumptions, directs the nurse to be clear about relevant data and to be sensitive to assumptions that may not be based on adequate data. The third step, to list all options, is intended to prompt the nurse to think carefully about all possible actions, rather than fall into the temptation to dichotomize the possible answers (e.g., withdraw all treatment or continue all treatment, accept the patient's decision or do not accept it, etc.). The fourth step is the point at which the nurse must bring to bear considerations related to ethical principles, relevant professional norms, laws, policies, and personal values. In this step, each option is evaluated against these touchstones or criteria. Finally, having evaluated each option, the final decision is made as the fifth step. Most ethical dilemmas are multifaceted, with conflicting demands. The case studies that follow in this chapter will demonstrate the complexity of these challenges, the need to address them in a methodical and logical process, and the essential caring role of the nurse in responding to such dilemmas.

Box 70.1 Steps of Ethical Problem-Solving

1. Define the Problem

   Differentiate clinical problems, such as uncertainty or disagreement about prognosis, from ethical problems, such as determining how to balance duties to provide benefit and duties to respect autonomy. Assure that everyone identifies the same issue.

2. Clarify Facts and Assumptions

   Differentiate known facts from assumptions about the situation, such as presumed motives of family members; assure that all parties have access to the same facts.

3. Develop a List of All Options

   Differentiate known facts from assumptions about the situation, such as presumed motives of family members; assure that all parties have access to the same facts.

4. Evaluate All Options

   Consider relevant laws, policies, and ethical principles; address rights, duties, and interests of all involved.

5. Choose the Optimal Option and Implement

Common Ethical Dilemmas

Case Study 1: Determining Decisional Capacity

A 75-year-old woman with a 15-year history of coronary artery disease, hypertension, diabetes, and heart failure entered the hospital with a left-sided cerebrovascular accident (CVA) that has left her partially aphasic, hemiparetic, and causes her to aspirate food of any consistency. Seven days after the stroke, her mental status was unclear, and there was a disagreement as to whether or not she had decisional capacity. She was able to answer "yes" and "no," although the responses were inconsistent. The attending physician was convinced that the patient lacked decision-making capacity while two family members (her daughter and younger sister) were equally convinced that she had decisional capacity. The patient did not have an advance directive. The patient's husband stated that they never held specific or detailed conversations about preferences for life-sustaining treatment. Until her stroke, she was active in her retirement and enjoyed gardening. He believed that she would not want to live in a condition that would not allow her to function as fully as she was prior to the CVA, but he was ambivalent about the placement of a feeding tube. The patient's family (daughter and sister) insisted that a feeding tube be placed because not doing so was "killing her." The attending physician and the rest of the interdisciplinary healthcare team were opposed to placing the feeding tube. In fact, several nurses who cared for this patient during previous hospitalizations for heart failure claimed that the patient told them that she did not want to be sustained by artificial means. The neurological consultant verified that, at this point, further significant recovery was unlikely due to dense damage to the cerebral cortex. The team believed placing a feeding tube was "potentially inappropriate." The advanced practice registered nurse was concerned about whether the patient would have wanted it and whether it would serve her best interests in the long term. She needed help to resolve this conflict.

Goal-Setting and Advance Care Planning

Patients with advanced disease or near the end of life, their families, and healthcare providers may encounter a variety of ethical dilemmas and subsequent choices. Although moral questions can arise about any aspect of nursing practice, including informed consent and duties to colleagues, the issues most frequently encountered in palliative care center around end-of-life (EOL) decisions. These include withholding or withdrawing treatment (e.g., mechanical ventilation, hemodialysis, cardiopulmonary resuscitation, and cardiac assist devices), concerns about use of medically administered nutrition and hydration (MANH), requests for hastened death, and palliative sedation.

For the most part, ethical analyses of these issues are grounded in patient choices, goals of care, preferences, prognosis, and communication. However, there are many important social, cultural, professional, and legal influences that have made these choices complex. The continual expansion of technological options and biomedical interventions, particularly over the past few decades, has enabled the medical profession to prolong life through sophisticated interventions before adequate bioethical norms have been established. As a consequence, it is usually more helpful to focus on patient preferences for *outcomes* of treatments rather than preferences or choices for *specific treatments*.[8] Clearly, this requires careful and repeated discussions with patients and their families. As can be seen in Case Study 1, it would have been much more helpful to know the patient's feelings and attitudes about what states or conditions would have been acceptable to her rather than general statements about use of "artificial means."

The pace and demands of healthcare today add to the challenges of addressing ethical issues in the clinical setting and may lead to hasty and arbitrary decision-making. According to Levine-Ariff, "It is only with a thrust toward preventive ethics that decisions can be thoughtful and beneficial to patients and families."[9(p. 169)] "Preventive ethics" can be thought of as standards and norms that, when adhered to, can minimize the frequency with which difficult conflicts and dilemmas occur. The use of advance care planning is an example of a "preventive ethics" intervention that nurses can implement on an individual level.

Because of the many difficult decisions that will be faced by most people as they age and experience serious illnesses, assuring that thoughtful discussions take place before serious illness occurs can be quite helpful in preventing later uncertainties and dilemmas (see Case Study 1). *Advance care planning* is a process of communication and documentation to identify patients' preferences about goals of care and to identify an authorized proxy who can provide competent, confident, and informed representation for choices when the patient is unable to express wishes. *Advance directives* are written instructions to healthcare providers that are established before the need for medical intervention. Advance directives have three major purposes: to provide a mechanism to enable providers to respect patient autonomy in situations in which the patient cannot express his wishes, to provide guidance to healthcare professionals and family members regarding how to proceed with decision-making about life-sustaining interventions, and to provide immunity for professionals from civil and criminal liabilities when certain stated conditions are met.

A *living will* is one type of advance directive which is often accompanied by a *durable power of attorney for healthcare* (DPAHC) or *healthcare proxy*. Living wills are used to declare wishes to refuse, limit, or withhold life-sustaining treatment under such circumstances that the individual is incapacitated or unable to communicate, while the DPAHC authorizes the agent or proxy to make all healthcare decisions, presumably acting as the patient would have. A living will, as the patient's own treatment preference, takes precedence over the DPAHC if there are conflicts. However, in many states, the living will statute specifies that this document is only in effect when the patient is terminally ill, as determined by a physician, and thus it may not be helpful in situations such as major cerebrovascular accident, significant dementia, coma, or other serious illnesses that are not considered inevitably terminal. Unfortunately, because predicting and outlining all possible choices regarding healthcare scenarios is difficult, advance directives are rarely specified as precisely as needed,[10] especially when a disease progresses and the context of the situation changes. Despite their shortcomings, advance directives are the best instruments we have to ensure that an individual's goals and preferences for care are met.[10]

It has been more than two decades since the Patient Self-Determination Act (PSDA) was made law in 1990, and empirical studies reporting effectiveness of advance directives continue to produce mixed results. In a systematic review and meta-analysis of the efficacy of advance care planning, Houben and colleagues[11] found that none of the studies limited to completion of advance directives explored the impact on preferences for EOL care and the actual receipt of end-of-life care. However, meta-analysis of those studies that included advance care planning discussions with completion of an advance directive yielded an increased likelihood of receiving EOL care that was in concordance with patient preferences. To that end, Johnson and colleagues[12] suggest that, in order to have a solid foundation of evidence of clinical effectiveness of advance care planning and completion of advance directives, conceptual clarity regarding "concordance," adequate attention to statistical methods, and valid and reliable measures must be considered at the onset of any research study. Nonetheless, advance care planning is an essential process that should begin to take place at the point of diagnosis and be revisited throughout the course of the disease trajectory to ensure that patients' preferences for care are honored.

Other forms of advance directives include out-of-hospital *do-not-attempt-resuscitation* (DNAR) orders and the *Five Wishes*,[13] a detailed guide for discussions of preferences for EOL care. The Five Wishes document helps individuals who are seriously ill and unable to speak for themselves express how they want to be treated from a medical, personal, emotional, and spiritual perspective. In addition, this unique document helps patients discuss their wishes with family and the healthcare team prior to loss of capacity and can be used in all 50 states and in all countries around the world (available in 28 languages); however, it meets the legal requirements for an advance directive in only 42 states and the District of Columbia. In the other eight states, the Five Wishes document can be included with the state's required form.

Healthcare advance directives differ widely in format and content, making the already complex issues that palliative care nurses face even more difficult. Additional barriers exist when patients transfer from one care facility to another and the requirements change or the previously existing document is not incorporated or honored. In addition, some advance directives are not sufficient to direct care in many healthcare institutions until a physician's order is written in the medical record. These barriers have led to an attempt to remedy these problems through the creation of other methods such as *physician orders for life-sustaining treatment* (POLST)[14] and *medical orders for life-sustaining treatment* (MOLST).[15] The overall aim of these forms of advance directives is to improve the communication of personal wishes about life-sustaining treatments, resulting in higher quality medical care that is consistent with patient choice.

The POLST Paradigm, as the concept is called, was originally developed in Oregon to improve EOL care by overcoming many of the shortcomings and pitfalls of advance directives. Because the POLST document is designed to translate shared decision-making into actionable medical orders and be long-lasting and portable across treatment settings, it can be posted on the patient's refrigerator or on the front of the patient's medical record, where it can be easily located by emergency medical personnel and other healthcare providers. The POLST form provides specific treatment orders for mechanical ventilation, antibiotics, cardiopulmonary resuscitation, and MANH and is recommended for persons who have a life-limiting disease, who might die in the next year, or who want to further define their preferences for care and treatment in order to help prevent initiation of unwanted, disproportionately burdensome, and extraordinary treatment.

Other states have adopted similar programs with different names although all share the same core elements with similar forms (e.g., medical orders on scope of treatment [MOST]; physician's orders on scope of treatment [POST]; and transportable physician orders for patient preferences [TPOPP]). The National Consensus Project for Quality Palliative Care's third edition of the *Clinical Practice Guidelines for Quality Palliative Care*[16] recommends that the POLST model be adopted nationwide because it more accurately reflects treatment goals and ensures that the information is transferable and applicable across all healthcare settings. Unfortunately, many state statutes require modification before this goal can be reached. Evidence, however, continues to support the implementation of POLST form completion and its relationship with preference concordance for less life-sustaining treatment.[17]

Nursing responsibilities related to advance care planning include initiating conversations about patient overall goals and specific wishes related to hospitalization, use of cardiopulmonary resuscitation, and other forms of advanced life support. These discussions will be most helpful if they focus on values rather than specific treatments. Patients and families should be asked about the existence of advance directives and be educated about the formal documents, their completion, and the process of advance care planning.

Do Not Attempt Resuscitation Orders

As noted, decisions about the level and type of interventions to be used must stem from consensus about the goals of care. For patients in acute care settings and those who have not yet elected to focus on comfort rather than cure, the specific issue of resuscitation status is a frequent source of distress for clinicians as well as for patients and families. In addition to discomfort and inexperience with the topic, there continues to be widespread misunderstanding about the efficacy of cardiopulmonary resuscitation (CPR) efforts and the meaning of decisions to withhold CPR in the event of an arrest.

Although survival rates following in-hospital cardiac arrest have improved over the past decade, currently, approximately half of all adult patients achieve return of spontaneous circulation following an in-hospital cardiac arrest, and less than 20% survive to hospital discharge.[18] This success rate has changed little in the 50 years since the technique of CPR was first developed. The relative ineffectiveness of CPR reflects the inappropriate widespread use of resuscitation efforts in situations in which multiple preexisting chronic illnesses have led to an irreversible state and death is inevitable. Unfortunately, the public has little understanding of what actually occurs in CPR, the limited benefit except in situations of single-organ disease and immediate intervention, and the potential for cognitive impairment if circulation is restored.[19]

Clinicians, too, may inadvertently contribute to misunderstandings about this issue in several ways. In addition to the tendency to avoid discussions of goals of care, too often the topic of resuscitation status is raised in the form of a question to patients, or more commonly to families, as "What do you want us to do if his heart stops?" (see Table 70.1). This approach reflects a well-intentioned but misguided attempt to identify patient and family preferences. It is misguided in that it places full responsibility for decision-making on the shoulders of family members and implies that it is possible to restore circulation through CPR.

As part of improving the standard of care in any institution, nurses can encourage providers to adopt the newer acronym, "DNAR." The American Heart Association, the recognized experts in emergency cardiac care, converted to the acronym "DNAR" (do not attempt resuscitation), rather than the former "DNR" in their 2005 standards,[20] signaling recognition that CPR, with its current wide application, more accurately is an *attempt* to restore cardiac function. This attempt is most often unsuccessful, and this change in language will hopefully facilitate recognition that a DNAR order does not entail a decision to allow a preventable death to occur. Rather, a DNAR order indicates a decision to withhold a very invasive and aggressive intervention that has little chance in promoting survival to hospital discharge.

Clarification of resuscitation status is best done as part of overall care planning. All nurses can play a key role in raising this topic, encouraging sensitive but straightforward communication and facilitating discussion. Because the intention to use CPR in the event of an arrest is the default in virtually all healthcare settings today, resuscitation status must be addressed in every situation of life-limiting or serious illness. This is particularly important when patients change care settings or begin care with new providers, such as occurs with admission to a long-term care facility, home healthcare, or home hospice.

Although use of DNAR orders is the standard method to indicate to healthcare personnel that CPR is not to be used, these orders are only effective within the facility in which they are issued.

Table 70.1 Phrases to avoid and phrases that can be more helpful

Do not say	Do say
"What do you want us to do if your loved one's heart stops?"	"We need to talk about where we go from here if your loved one's condition continues to worsen."
"Would you want us to do CPR if your loved one's heart stops?"	"There are many things we can do, but it's very important that we talk together about what your loved one would want done in this situation. Have you and he/she ever known anyone who was this ill . . . did he/she say anything about what he/she would want in a situation like this?"
"We need your permission to do a (tracheostomy, PEG, angiogram, etc.)."	"Given what we've discussed about your loved one's situation and the most likely benefits and burdens of the procedure, we need your help to know if he/she would want us to proceed with the (tracheostomy, PEG, angiogram, etc.)."
"We'll do whatever you want us to . . . it's your decision . . . we'll support whatever you decide."	"We have to make some decisions about where to go from here. It's our job to give you information about the medical facts and our recommendations, and we need you to help us know what would be important to your loved one now. Then, we need to talk and come up with a plan together."
"We need to withdraw care."	"We recommend stopping the dialysis based on your husband's goals of care. We will not abandon you or your husband and will still use everything we can to make sure he is comfortable."

The need to have portable orders and valid indicators of DNAR status for patients moving between facilities or patients being cared for at home has led to the creation of out-of-hospital forms and identifiers. In some cases, this has been specific clauses in the living will, and, in other cases, a specific out-of-hospital standard order form has been developed. Unlike most advance directives, the out-of-hospital DNAR document is a valid physician order that takes effect as soon as it is signed; it is not limited by the patient's diagnosis or terminal status. When available, these forms should be initiated when the decision to forego CPR is first made so that patients can take them with them as they are discharged or transferred between facilities.

A frequent challenge nurses face is how to manage situations in which they perceive the patient's condition is deteriorating and no one has addressed the issue of resuscitation status with the patient or family. Common concerns are that initiating such a discussion is outside the boundaries of the nursing role, that physicians will be angry if the nurse raises the topic, or that patients or families will be upset. It is important for nurses to recognize that it is within the professional role of nursing to identify the need to develop consensus as to goals of care and treatment plans and to facilitate discussions surrounding difficult decision-making.

Proxy Decision-Making

Because patients with serious illness frequently lack cognitive capacity at some point during the illness, professionals must rely on family or friends to represent their wishes and participate in decision-making. This creates a number of possible areas of conflict and uncertainty, including the need to make careful assessments of capacity, questions about the moral authority of family and friends to make decisions for patients, and, in some cases, the need to manage conflicts among and between families and the care team, as occurred in Case Study 1.

"Incompetency" refers to a status that is conferred by a court, establishing the inability of an individual to act as an autonomous and legally responsible person. Only the court can make a determination of *competence*; clinicians provide evidence to the court regarding the *capacity* of the individual, including data about diagnosis, cognitive and functional ability, and likelihood of recovery. The elements of a clinical determination of decisional capacity include the patient's ability to understand what decision is being made; to understand the alternative to the proposed intervention; to understand the relevant risks, benefits, and uncertainties related to each alternative; to maintain consistent reasoning; and to clearly communicate the desired decision.[21] An individual who has been deemed "incompetent" loses the right to make all decisions, including healthcare decisions, and must have a guardian appointed by the court to manage all affairs. Clinicians, therefore, cannot establish competency, but instead do have an ongoing responsibility to assess the capacity of the patient to participate in decision-making.

When patients are not able to express their wishes or make decisions and do not have a designated healthcare agent, family members are asked to act as proxies. Although this is common practice, states vary in the extent to which this is authorized by law and the precise specification of which family members have priority in decision-making. The moral basis for allowing one adult to make decisions for another is the assumption that family members are committed to furthering the best interests of the patient and that family members who share background, experiences, religion, and culture with the patient are well-equipped to represent the preferences and values of the patient. These assumptions are usually quite valid, but there are situations in which nurses question the ability of the family member to act as a valid proxy for the patient. These situations are difficult, and nurses must be prepared to seek guidance from the hospital ethics committee or hospital legal counsel, as well as collaborate with physicians and social workers on the care team.

Proxy decision-making, even under the best of circumstances, can be very burdensome to families already stressed by the realization of the seriousness of their loved one's illness. Several studies have demonstrated that family members are not able to consistently identify the preferences of their ill relative even when an advance directive is in place.[22,23] As mentioned earlier, this is related to reluctance to discuss EOL issues before a crisis and, when discussion does occur, the likelihood that the discussion was of a general nature and does not necessarily apply to the very specific decisions that have to be made in situations of prognostic uncertainty. An additional common occurrence is lack of consensus among family members about specific decisions, such as limiting treatment, DNAR status, or referrals to hospice.

In the absence of formal advance directives, intrafamily conflict, as exemplified in Case Study 1, is not uncommon. In that case, the patient's husband seemed to be leaning against use of MANH, but the patient's daughter and sister felt compelled to provide MANH. Even if the patient had completed a DPAHC that established the husband's authority as a decision-maker, the nurse can provide significant assistance to the family, as a unit, in providing education, as discussed in the next section, and helping the family come to consensus.

There are several steps the nurse can take in an effort to prevent or minimize concerns related to proxy decision-making, particularly when initiating palliative care services. First, all patients who have a serious illness and do not have a DPAHC should be asked to identify a proxy to make decisions if they should become unable. This can be done on admission to the hospital or any other healthcare delivery system in a nonthreatening manner, simply pointing out that sometimes patients become too ill or too sleepy due to medication. This will enable the team to know, if there are disagreements later, who has the strongest claim to the decision-maker role. Second, the time to obtain information about the patient's lifestyle, values, and preferences is before specific decisions about pursuing invasive diagnostic tests or procedures are needed. Talking with family members about what the patient was like, what he or she enjoyed, and what was important, can be helpful in later discussions. Third, when it is necessary to ask a family proxy to provide input into the plan of care, it is essential to address the task as one of helping the clinicians to know what the patient would have wanted. This can be done by referring back to earlier discussions about what was most important to the patient. The goals here are twofold: to minimize the burden of responsibility the family member might feel and to remain focused on the ethical mandate to act according to the patient's wishes, not the family members' wishes. In addition to Table 70.1, which provides some examples of ways to phrase questions that are not helpful and some ways that can be more useful in supporting family decision-making, there are a number of more detailed communication suggestions that have been published.[8]

Medically Administered Nutrition and Hydration

A fundamental caregiving task is to provide food and fluids. The provision of nutrition and hydration symbolizes the essence of care and compassion, and eating serves as a symbol of health. In most societies, celebrations involve eating, and through these traditional social events we communicate sharing and well-being. Clearly, human life is represented as social and communal through the provision of food.[24] When a loved one has an advanced illness, these opportunities wane, and, when one is dying, they are often lost. However, providing MANH is not synonymous with eating or feeding another person. In health, people eat in a socially acceptable form, with others, in a social setting. MANH do not share these social characteristics. The technology of feeding tubes was developed to address specific temporary medical problems (e.g., postsurgical gastric motility issues, swallowing impairment following a stroke in a patient expected to recover). However, the use of feeding tubes and medically provided nutrition and hydration has become widely used in patients with very poor prognoses and for those with little likelihood of regaining functional abilities. Few decisions are more value-laden than those to withhold or withdraw a medical intervention that is thought to be able to prolong life. As with all decisions about the use of any medical device or treatment, this decision should be based on the patient's goals of care, the medical need, and the burdens and benefits of the treatment.

In general, patients (or their surrogates) have the right to withhold or withdraw MANH if they believe that the burden or risks outweigh the benefits. There is widespread agreement in ethics and law[25–27] that patients or their surrogates have a right to choose or refuse MANH. All decisions about nutrition and hydration should be made in light of patient's goals and outcomes of care. These goals of care may change during the course of the disease or as the disease progresses and the patient's cognitive and physical functioning decline. Consequently, nurses should create opportunities for discussion and negotiation of goals and priorities of care with the patient and family/surrogate on an ongoing basis.

MANH requires the placement of a temporary or permanent feeding tube or the initiation of intravenous access. These interventions are associated with risks, including bleeding, tube displacement, and infection, as well as the potential need for repositioning and replacement.[28] In patients with impaired renal function, intravenous fluids may promote peripheral or pulmonary edema and increase the need for suctioning.[28] Tube feedings do not appear to prevent aspiration pneumonia and may increase the risk as compared to those patients who do not take anything by mouth.[28] Other potential side effects of tube feeding include diarrhea, nausea, and vomiting.[28] Teno and colleagues concluded that feeding tubes are not associated with prevention or improved healing of a pressure ulcer.[29] In fact, hospitalized nursing home residents who received a percutaneous endoscopic gastrostomy tube (PEG) were 2.7 times more likely to develop a new pressure ulcer and those with a pressure ulcer were less likely to show healing of the ulcer when they had a PEG tube inserted. Similarly, there is particularly strong evidence confirming the failure of PEGs and tube feeding to prolong survival in states of advanced dementia.[30–32]

Many patients and family members have deep concerns about the issue of "hunger" and "starvation." Contrary to what many believe, a patient with a terminal disease, who is often anorexic from the effects of the disease, is unlikely to be bothered by hunger.[33] In fact, many patients in whom the disease is progressing tend to report a complete lack of hunger. Evidence suggests that natural physiological processes that accompany the cessation of food and fluid intake naturally suppress both hunger and thirst. In addition, there is strong consensus among palliative care clinicians and oncology professionals that use of parenteral hydration in terminally ill patients is most often associated with unpleasant symptoms of fluid retention and overload.[28] Nursing interventions that can assist with the palliation of symptoms associated with dry mouth or thirst include small sips of oral intake, ice chips, meticulous mouth care, and lubrication of the lips. Involving caregivers, family members, and loved ones in this activity may replace the family's desire and need to feed with another caregiving activity that can provide the family with the opportunity to provide physical comfort.

Financial implications of these decisions and implications for discharge planning and home care also need to be considered. Some hospice programs cover the cost of MANH based on the individual plan of care and the goals of care, but others do not. Some extended-care facilities (i.e., nursing homes) mandate medically provided nutrition and hydration when a person stops eating and/or drinking, often related to misunderstanding and concern about state regulations or related to philosophy and religious missions. Consequently, discussions with families about decisions to use ANH, as in Case Study 1, should include consideration of these factors. In Case 1, the nurse would have several responsibilities, including clarifying the facts about the patient's previously stated wishes, educating all family members regarding the likely benefits and burdens of tube feedings, and focusing discussions with physicians and family members on what was known about the patient's values and preferences.

Despite the lack of proven benefit in states of irreversible and advanced illness, MANH will remain an emotionally laden topic and one of the most difficult decisions to make. There is a persistent widespread belief that healthcare professionals have a moral duty to feed all patients and that the benefits of ANH always outweigh the burdens. This misunderstanding, in combination with concerns about causing suffering, is a significant barrier to careful ethical evaluation of the decision to use or withhold ANH. Assuring informed decision-making about this aspect of the care plan often must begin with addressing the concerns of the care team and providing the necessary education about this issue.

Case Study 2: Withdrawal of Life Support in the Intensive Care Unit

Mrs. Black is a 40-year-old, divorced Caucasian woman who had been diagnosed with metastatic colorectal adenocarcinoma 2 years ago. She had undergone three cycles of adjuvant chemotherapy and radiation to reduce tumor burden and had successfully survived a colorectal resection with ileostomy placement. Over the past 2 years, she described her quality of life (QOL) as meaningful due to her relationship with her two college-aged children. Unfortunately, her liver metastasis progressed, and the last imaging revealed widespread lung metastasis with mediastinal involvement. While at home over Spring Break, her sons found her having difficulty breathing and called 911. Upon arrival to the emergency department (ED), additional imaging revealed the thoracic lesion was now compressing her bronchus, and she was taken to the operating room for stent placement as a palliative measure. This was able to be done, and she was transferred to the intensive care unit (ICU)_, intubated, and placed on mechanical ventilation. Several attempts, over the course of the next 2 weeks, were made to extubate her, but she was unable to maintain a patent airway without the positive pressure of the ventilator. Each time the ventilator support was reduced, Mrs. Black became anxious and fearful, even with the use of increasing doses of morphine and lorazepam. She was awake and alert, able to write notes, and wanted to see her sons. On rounds, the ICU physician mentioned to the team that it was time to consider performing a tracheostomy since Mrs. Black could not be intubated, and, after all, she was young. Her nurse Camille was concerned that this would just subject Mrs. Black to another procedure that would not change the eventual outcome. Camille was also uncertain whether anyone on the healthcare team had discussed Mrs. Black's condition with her and her sons and the high probability that she would never be able to leave the ICU. On the other hand, Mrs. Black was awake and oriented and withdrawing life support (e.g., extubating her) felt cruel—how could this be done without causing pain and suffering to not only the patient but her family?

Hastening Death

A central issue in decision-making in states of serious illness is the moral acceptability of actions that can be seen as hastening death. As has been noted throughout this chapter, it is well-established in Western bioethics that competent patients have an almost unlimited right to accept or refuse medical interventions, regardless of the established efficacy of the intervention or its necessity for survival. Supporting and advocating for this right is a critical function of the nurse and one which has been identified as a frequent source of ethical distress.

The recognized right of the individual to elect to stop life-sustaining technology, such as mechanical ventilation or hemodialysis, has been used by some as the basis for arguing that there is no difference between this act and acts that intentionally hasten death, including both euthanasia and assisted suicide. Arguments that there is a difference usually rely on the distinction between allowing a death caused by disease (allowing natural death to occur) as occurs when removing unwanted or ineffective life-prolonging therapies such as mechanical ventilators and dialysis, and killing, which entails being the direct cause of death (see Case Studies 1 and 2). There is ongoing debate in the bioethics community about whether this is a morally relevant distinction, and each nurse who cares for patients with life limiting disease will have to carefully identify his or her own beliefs.

Euthanasia is defined as an intentional act performed for the purpose of causing the death of another for reasons of mercy, whereas *assisted suicide* is the provision of assistance in some form (e.g., supplying lethal medications or instructions) to an individual who then acts to take his or her own life. Euthanasia in all forms is illegal in the United States and is condoned by none of the professional associations (see Box 70.2). However, assisted suicide (also termed physician-aid-in-dying [PAD], medical aid-in-dying [MAID], and physician-assisted suicide [PAS]) has been legalized in Oregon since 1997. Since this time, Death with Dignity laws are now recognized in the states of California, Colorado, Vermont, Washington, and the District of Columbia.[34] Given that PAD/PAS is legally sanctioned in these states and that legislation in additional states is anticipated, guidelines to assist palliative and hospice nurses on how to respond when hastened death is requested are germane to the delivery of comprehensive hospice and palliative care. At this time, professional nursing organizations do not condone nurses actively participating in assisted suicide/MAID (Box 70.2). In 2017, the Hospice and Palliative Nurses Association developed guidelines for the role of the registered nurse and advanced practice registered nurse when hastened death is requested.

Recent data report that typical patients who seek PAS/MAID are older, white, well-educated, and have cancer; most of these patients state that impending loss of autonomy is the primary motivation for requesting PAD/PAS.[35] Since the law passed in Oregon in 1997, a total of 1,749 terminally ill adult patients have had prescriptions written and 1,127 patients have died from ingesting the medication.[36] In 2016, most patients seeking PAD/PAS were enrolled in hospice care. In Oregon, 133 died ingesting medication (88% enrolled in hospice); in Washington, 192 died (77% enrolled in hospice).[37]Although no healthcare professional is obligated to engage in PAS, PAD, or MAID, all members of the interdisciplinary healthcare team will need to determine how to balance patients' rights with personal values and professional obligations.

Box 70.2 Position Statements from Recognized Professional Organizations

Medically Administered Hydration and Nutrition

- Hospice and Palliative Nurses Association (HPNA). *Position Statement: Artificial Nutrition and Hydration in Advanced Illness*. Pittsburgh, PA: Hospice and Palliative Nurses Association, 2011.
- National Hospice and Palliative Care Organization (NHPCO). *Position Statement: Artificial Nutrition and Hydration Narrative and Statement*. Alexandria, VA: National Hospice and Palliative Care Organization; 2010.
- American Nurses Association Position Statement (ANA). *Position Statement: Nutrition and Hydration at the End of Life*. Silver Springs MD: the American Nurses Association; 2017.
- American Academy of Hospice and Palliative Medicine (AAHPM). *Position Statement: Artificial Nutrition and Hydration Near the End of Life*. Glenview, IL: American Academy of Hospice and Palliative Medicine; 2013.

Physician-Assisted Suicide/Physician-Assisted Dying

- Hospice and Palliative Nurses Association (HPNA). *Position Statement: Physician Assisted Death/Physician Assisted Suicide*. Pittsburgh, PA: Hospice and Palliative Nurses Association, 2017.
- American Nurses Association Position Statement (ANA). *Position Statement: Euthanasia, Assisted Suicide, and Aid in Dying*. Silver Springs MD: the American Nurses Association; 2013
- National Hospice and Palliative Care Organization (NHPCO). *Commentary and Resolution: Physician-Assisted Suicide*. Alexandria, VA: National Hospice and Palliative Care Organization; 2010.
- American Academy of Hospice and Palliative Medicine (AAHPM). *Position Statement: Physician Assisted Dying*. Glenview, IL: American Academy of Hospice and Palliative Medicine; 2016.
- International Association for Hospice and Palliative Care. *Position Statement: Euthanasia and Physician-Assisted Suicide*. Houston, TX: International Association for Hospice and Palliative Care; 2016[62]

Palliative Sedation

- Hospice and Palliative Nurses Association (HPNA). *Position Statement: Palliative Sedation*. Pittsburgh, PA: Hospice and Palliative Nurses Association; 2016.
- American Academy of Hospice and Palliative Medicine (AAHPM). *Position Statement: Palliative Sedation*. Glenview, IL: American Academy of Hospice and Palliative Medicine; 2014.
- National Hospice and Palliative Care Organization. *Position Statement: Use of Palliative Sedation in Imminently Dying Terminally Ill Patients*. Alexandria, VA: National Hospice and Palliative Care Organization; 2010.
- National Hospice and Palliative Care Organization. *Position Statement: Palliative Sedation in Hospice and Palliative Care*. Alexandria, VA: National Hospice and Palliative Care Organization; 2012.

Given the legal status of specific actions related to PAD/PAS, ethical conflicts can arise among those individuals who support the actions permitted in the statute and those who may hold a different moral position. In an attempt to improve professional tolerance around such discussions, healthcare providers should not lose sight of serving the good of the patient, including patient preferences and religious and cultural values. These situations require very careful attention from the nurse, awareness of legal and ethical considerations, and a well-developed and collaborative plan for responding.

The first, and perhaps most important, responsibility of the nurse is clarification and assessment. The expression of thoughts of hastening death may be an accurate report of a serious intention, it may be a relatively off-hand comment, it may be an expression of distress prompted by unrelieved symptoms, or it may be intended as a test of the nurse's views about hastening death. In addition to clarifying the meaning of the patient's statements, the desire for hastened death should always prompt a thorough evaluation of the adequacy of symptom management, reassurance about commitment to address future problems, advance care planning, and hospice. There are a number of guidelines developed by professional associations and groups to assist the clinician in responding to requests for hastened death (see Box 70.2). Reassessing and focusing on palliative care efforts to relieve distress are essential. Assessment of the emotional state of the person is necessary when the request for hastened death is affected by depression, anxiety, or delirium.

Cardiovascular Implantable Electronic Devices (CIEDs), Palliative Sedation, "Nonbeneficial Interventions," Voluntary Stopping Eating and Drinking

There are some specific issues that present particularly challenging questions in palliative care. These are the acceptability and methods of withdrawing life-sustaining interventions that consist of cardiac assistive devices (pacemakers, automatic internal cardio-defibrillators [AICD], left ventricular assistive devices [LVAD]), concerns about requests for potentially inappropriate treatments or nonbeneficial interventions (formerly known as "futility"), palliative sedation, and voluntary stopping of eating and drinking (VSED).

Cardiovascular Implantable Electronic Devices

One of the most concrete examples of the complexities created by advancing technologies is the situation of patients who have elected to forego continued use of cardio-assistive devices in order to allow a peaceful death. There are a number of implantable mechanical assistive devices intended to either support or replace normal cardiac electrical and mechanical function, including LVADs, right ventricular assistive devices (RVADs), total implantable hearts (TIH), internal AICDs, and pacemakers. Each of these raises unique issues.

Internal automatic cardio-defibrillators are very commonly used in the United States as treatment of recurrent ventricular fibrillation. Pacemakers have been a long-standing therapy for bradyarrhythmias and combined AICD-pacemakers are recommended for some forms of heart failure. Hundreds of thousands of patients in the United States have cardiovascular implantable electronic devices (CIEDs), primarily due to the nearly 600,000 individuals who have end-stage refractory heart failure.[38] It is therefore very likely that palliative care nurses will find themselves caring for patients with either or both of these devices. In most cases, both AICDs and pacemakers are on-demand therapy; that is, they are programmed to deliver therapy only on demand (when heart rate decreases or a lethal arrhythmia develops). Therefore, their function should be disabled when the plan of care is based on a goal of allowing a peaceful death with no further intervention. AICDs should be turned off so that they will not deliver a shock as the heart rate falls or ventricular arrhythmias occur. Demand pacemakers can have the rate and sensitivity decreased so they do not prolong the dying process. Cardiologists or cardiac technicians usually must be called and requested to make these changes using the device programming magnets.

When cardiac function is dependent on active device operation, as is the case with some pacemakers and most cardiac assistive devices, there are more difficult challenges and unresolved questions. Some argue that discontinuing a cardiac assistive device, with the expectation that death will follow, is no different, morally, than discontinuing mechanical ventilation for a patient who has elected (or family has elected) to have life-sustaining therapy discontinued. However, others believe that the act of deactivation constitutes euthanasia or PAS.[39] The crucial difference lies in the primary intention: termination of a life versus termination of a therapy. Thus, death that follows withdrawal of LVAD support occurs from the underlying heart failure. As the burden of these devices may outweigh benefits when patients' goals and preferences change, patients have the right to request deactivation.[40,41] This right is well-accepted and supported by the American College of Cardiology Foundation (ACCF) and the American Heart Association (AHA).[42] In fact, the Heart Rhythm Society[43] issued a consensus statement that asserts that "withdrawal of a treatment is a personal right of the patient" and is ethically and legally permissible.

Since 2002, LVADs have been considered "destination therapy" for patients who are ineligible for transplant or for those patients whose estimated 1 year mortality is greater than 50% with medical therapy.[44] LVADs will alter EOL trajectories. Although intended to prolong survival related to heart failure, LVADs have the potential to decrease the overall QOL of these patients because of serious infections, neurological complications, and device malfunction.[45] Numerous research studies[44,46,47] have shed light on the importance of the ethical obligations clinicians hold to provide significant emotional support to these patients and their families.

When caring for the patient with an implanted cardiac device, the nurse has several responsibilities. First, the exact status of the device's operation has to be determined. As with all components of the palliative care plan, the plan for adjusting the device should stem from a clear understanding of the patient's goals of care. If, for example, the goal is to make the most of whatever time is left and there is hope for more time, all cardiac devices should remain active and in place. On the other hand, if the patient is actively dying or has expressed an informed desire to remove any therapy that could interfere with the dying process (whenever that might occur), the devices should be inactivated (or turned to an inactive setting). Each of these decisions, of course, must be made in collaboration with the care team. If there is consensus about discontinuing a device on which cardiac function is entirely dependent, extra care must be taken to assure that the patient, family members, and the entire care team are in agreement. The timing of the discontinuation must be carefully considered and a plan to address likely symptoms put in place.

Palliative Sedation

There are a very small number of situations at the end of life in which patient symptoms cannot be adequately relieved despite multiple pharmacologic regimens. Despite the provision of evidence-based, state-of-the-art palliative care, some patients will continue to experience protracted, intense suffering toward the end of life. In these cases, the option of palliative sedation is sometimes raised. *Palliative sedation* refers to the use of medications to induce sedation, either intermittently or continuously, for the purpose of providing relief of intractable symptoms and suffering. The intention is not to cause death, but to provide symptom relief for a dying patient when all other efforts have failed.

In an effort to clarify the different types of palliative sedation and how each may be used, Quill and colleagues[48] outlined three definitions of sedation: ordinary, proportionate (PPS), and palliative sedation to unconsciousness (PSU). Although these definitions have helped to clarify the types of sedation, there remains great fear that access to these practices may become too easy. However, in a systematic review of the literature regarding palliative sedation and survival, Barathi and colleagues[49] found no evidence to suggest that palliative sedation has any detrimental effect on survival of patients with advanced cancer. In fact, they suggested that it is a medical intervention that should be included in the list of interventions to relieve suffering.

Despite these views and data, the wide variation in the reported use of palliative sedation and limited research evidence about best practice is likely a reflection of ambivalence and uncertainty about the ethical acceptability of the practice.[50] Perhaps the most common objection to palliative sedation is the belief that PPS and PSU will directly hasten death. Nevertheless, use of PPS and PSU does require also addressing other interventions, such as the continuation of oral medications and the administration of food and fluids.[50] In general, these other decisions should be made separately and before palliative sedation is begun. If there are adequate reasons to stop food, fluids, and other medications (i.e., if the patient is in the final stages of dying, has been refusing food and fluids, and other medications are not needed for promotion of comfort), there is no reason to insist they be used when palliative sedation begins. On the other hand, if nutrition and hydration were indicated before sedation, there may be good reason to continue their use or sedation should be stopped or lightened intermittently to offer food and fluid.

Case Study 2 is an example of a situation in which palliative sedation might be necessary. If Mrs. Black, who retained decisional capacity, chose to have ventilatory support withdrawn, it might be necessary to sedate her to the point of unconsciousness in order to prevent suffering. This act certainly would shorten her survival, compared to continuing mechanical ventilation. However, this act would be morally permissible and supported by the *principle of double effect*. This principle, well-established in bioethics, asserts that acts that are intended to achieve a "good" effect (in this case, respecting autonomy and preventing suffering) are permissible even if the act also carries with it an unintended "bad" effect (hastened death). In addition to intending only the good effect, this principle requires that the good not be achieved by means of the bad (i.e., the relief of suffering is achieved by the sedation, not by causing death), and the weight of the good achieved must be greater than the bad effect.[24]

Although many professional organizations (see Box 70.2) support the use of palliative sedation in carefully selected situations, all emphasize the importance of clarity in the intended objective (relief of suffering) and the need for thorough discussion and informed consent from the patient. In addition, all healthcare institutions providing palliative and EOL care should have a written policy about palliative sedation and the types of sedation that will be offered to patients if requested. This policy should be provided to patients or their proxies who ask about the possibility of having PSU in the future or request it when other interventions have failed to relieve intractable suffering. Moreover, if the healthcare institution offers PSU but an individual physician objects to its provision, the providers must make alternative arrangements for the care to be transferred to another provider or institution.

Given the importance of communication in the final stages of life, use of palliative sedation should be reserved for those few situations in which all other interventions have been ineffective and the patient finds continued consciousness to be intolerable. Clinicians have an obligation to describe as clearly as possible the likely scenarios for a patient who is considering palliative sedation and should work with patients, families, and the interdisciplinary team to establish a clear plan of care before sedation is initiated. This should include discussion about what life-sustaining treatments will be continued or withdrawn after the patient has been sedated.

Futility and Alternative Terminology

"Futility" is a term that refers to the inability of a specific intervention to lead to its intended outcome (e.g., prolonged survival, discharge from the hospital, shrinkage of tumor). Although the term "futility" continues to have widespread use in the medical community, several alternative terms have more recently been proposed to accurately reflect the medical judgment that there is no realistic likelihood of benefit to the patient based on the existing scientific evidence and a high likelihood of harm or suffering. These terms include: "withdrawing and withholding of nonbeneficial medical interventions," "potentially inappropriate treatments," and "not indicated interventions." Each of these descriptors, however, offer little assistance when confronting a disagreement about providing a particular treatment, where the other side in the argument sees the treatment as indicated and appropriate because it might offer some benefit.

Most recently, the American Thoracic Society, American Association for Critical Care Nurses, American College of Chest Physicians, European Society for Intensive Care Medicine, and the Society for Critical Care issued a policy statement regarding how to respond and manage requests by patients or surrogates for treatments that clinicians believe should not be administered.[51] This multidisciplinary statement recommends that the term "potentially inappropriate" be used rather than the term "futile" to describe treatments that have some minimal possibility of accomplishing the goal sought by the patients, but clinicians believe that competing ethical considerations justify *not* providing them. This collaborative statement goes on to assert that the term "futile" be restricted to rare situations where surrogates request interventions that simply cannot accomplish the intended physiological goal, such as continued ineffective chemotherapy. And, finally, it is recommended that clinicians not provide such futile interventions.[51]

Today, potentially inappropriate intervention disputes occur frequently with patients with advanced illness and their families and are one of the primary reasons for hospital ethics consultation. In fact, one large academic medical center estimates that 20% of patients in its ICU are receiving "futile treatment."[52] An example of a potentially inappropriate treatment is prolonged use of mechanical ventilation in a patient who has widely metastatic and incurable cancer (see Case Study 2). Over the past decade, clinicians have increasingly encountered situations in which patients and families request or demand therapies that the clinician believes have no meaningful chance of prolonging life or improving well-being. Over the years, there has been a growing consensus that the right of patients and families to accept or refuse therapies does not entail the right to demand therapies which the physician does not believe are medically justified. This stems from the principle of autonomy, which establishes the duty to refrain from interfering in the life choices of competent persons.

The gradual move away from the paternalism of the past and a commitment to supporting patient autonomy has unfortunately led to a tendency to shift the responsibility for decision-making entirely to patients and families. This is sometimes seen in the reluctance of clinicians to advise or guide patients and families in decisions and, instead, to present options in a completely impartial fashion. Not infrequently, families will express the wish to have "everything" done for their loved one. When this is said, the nurse or physician should respond by assuring the patient and family that they are heard and that their wish to receive all therapies that have any meaningful chance of maintaining or improving the patient's condition will be used. The use of shared decision-making should be emphasized from the start. As the condition of the patient deteriorates and it becomes apparent that continued interventions will not be helpful, it is best to set the stage for later decisions by affirming that the clinicians will provide honest and direct information and will identify when there are no further curative options, with assurances that the plan of care will always be discussed before changes are made. When the situation is such that CPR or other interventions are no longer indicated, this should be stated; patients or families should not be asked to give permission to withhold an ineffective intervention. If consensus appears to be unreachable, other resources, such as clergy or ethics consultants should be utilized. Although seeking guidance from the court may be required in intractable disputes, in general this should be viewed as a last resort, and thoughtful, interdisciplinary procedural approaches are preferable.

In Case Study 2, the nurse, Camille, may have believed that performing a tracheostomy on Mrs. Black would indeed be futile. Although the procedure could be safely performed, it would not save the patient's life or even allow her to recover enough to leave the ICU—she would always require mechanical ventilation. To address this issue, Camille would need to first validate her assumption about the location of Mrs. Black's tumor and the ineffectiveness of a tracheostomy to relieve the obstruction. Next, a care conference with the entire multidisciplinary team would have to be arranged to develop consensus about the best approach. If the team reaches agreement about the lack of any effective treatment options for the cancer, a plan would have to be developed, including who would talk with Mrs. Black and her sons, what recommendation would be offered, what options would be acceptable, and how to manage her symptoms when she was ready to discontinue mechanical ventilation.

Although it is becoming increasingly recognized that clinicians have not only the right but the professional duty to refrain from interventions that are harmful, it is essential to be cautious in judging interventions as "futile" or medically inappropriate. There are many treatments or therapies that offer neither cure nor improvement in patient condition, but which are effective in supporting survival, such as mechanical ventilation following anoxic brain injuries. Today, the claim of "futility" should not be used to justify withholding therapies in situations in which the clinician believes that the proposed therapy would accomplish its intended purpose but the resulting QOL would be undesirable. Judgments such as this reflect the subjective opinions and values of clinicians and are not a valid basis for withholding therapy against the wishes of patients and families.

Voluntary Stopping Eating and Drinking

Voluntary refusal of food and fluids is another option to hasten death and anecdotally seems to have increasing prevalence, specifically in states where PAS and MAID have not been legalized.[53] Persons with a terminal illness who retain decisional capacity may elect to stop eating and drinking; it is both legally and morally permissible. In contrast to PAS, VSED requires no action by a physician and requires no physical action by the patient. Persons who elect this approach usually die within 7–21 days.[53] In contrast, VSED in a non–terminally ill patient is usually considered a form of suicide and must be evaluated as such. The American Nurses Association (ANA) recently published a favorable position statement regarding VSED (see Box 70.2), yet almost no medical association, either in the United States or in Europe, has formally supported or taken a neutral position on the subject. Institutions should have established policies in place that address VSED and include educational offerings for the staff and family, safeguards for the patient (e.g., psychiatric evaluation), and ethics committee consultation when requested.

Nursing Issues, Moral Distress, and Compassion Fatigue

Decisions regarding ethical dilemmas and the choices that are necessary require thoughtful discussion and critical communication skills. Stemming from the priority of the principle of autonomy or self-determination, decisions about care should be made in accordance with patients' preferences for care, beliefs, and values. With increased medical technology, the advances in science, and conflicting interests of patients and families, nurses stand in a pivotal position to lead the way in assuring patient access to quality palliative care. This charge does not come without the risk of the nurse feeling like he or she is "in the middle," trying to provide the best possible care to the patient and supporting the family members while preserving personal values.

Nurses and other members of the interdisciplinary healthcare team daily face ethical and legal issues in decision-making related to EOL care in clinical practice. These dilemmas have a strong potential to provoke conflict among those involved in patient care, sometimes between professionals and sometimes between patients, families, and professionals. The ANA Code of Ethics states that nurses have the right to withdraw from providing care to patients when their own values conflict with that of patients so long as the patient's care can safely be transferred to another care provider. The ANA goes on to discuss the importance of "preservation of integrity." Specifically, Provisions 5 and 6 of the ANA Code of Ethics discuss moral self-respect and the influence of the environment on ethical obligations, moral virtues, and values. According to these provisions, nurses have a duty to remain consistent with both their personal and professional values and to possess character strengths such as compassion and patience. Although simply stated, these behaviors may be challenged when faced with ethical and moral dilemmas.

Close, personal relationships are often formed with patients and their families as palliative care nurses care for them over a prolonged period of time. Moral and ethical dilemmas, often associated with patient/family situations and healthcare environments, may leave the hospice and palliative care nurse feeling physically, emotionally, and spiritually drained. As nurses continue to be exposed to patients with greater healthcare needs, staff shortages, heavy and intense workloads, an aging workforce, and a lack of resources to work effectively, the opportunity to develop moral distress, moral fatigue, burnout, and compassion fatigue is a real possibility.[54]

Compassion fatigue is a term used to describe a stress response in a healthcare provider; it has been widely studied and is pervasive within the nursing profession.[54] Compassion fatigue is a state in which the compassionate energy that is expended by nurses outweighs the restorative processes and the ability to recover has been lost; it is the negative aspect of helping that can be related to the actual provision of care, the environment, colleagues, and/or beliefs about self.[55] *Burnout*, on the other hand, relates to work-related hopelessness; it is the inability to cope with job stress that produces feelings of inefficacy.[56] *Moral distress* is a phenomenon in which an individual knows the right action to take but is constrained from taking it.[57] Moral distress arises when one must act in a way that contradicts personal values and beliefs; *moral fatigue* is the consequence of continued moral distress.[57] For example, nurses might act in a way that is contrary to personal and professional values or be unable to translate moral choices into action. This creates anguish, and the consequences can be profound and have lasting effects.[58] Although nearly all healthcare professionals experience some moral distress during their tenure in caring for those who are ill, nurses seem to be at a higher risk.[59] Nurses who appear to be at a higher risk for compassion fatigue include those who are younger, who have a history of personal trauma and have not worked through issues related to that trauma, nurses working with large caseloads and/or long hours, those already experiencing professional burnout; nurses with inadequate training in effective communication or those less competent in communication, and nurses without adequate collegiate and personal support systems.[60]

According to Potter and colleagues,[61] the risk and incidence of compassion fatigue among nurses could largely be decreased with education regarding its existence, prevention, and coping strategies. Coping strategies, including self-care, are key to prevention of compassion fatigue. Integrating self-care activities, including self-compassion and mindfulness-based strategies, into professional workloads is not typically part of professional training, nor is it explicitly part of one's job description. One of the most crucial elements in dealing with moral distress is knowing *what* support is available and *how* to navigate the system in place. Ethics Committees are one source of support and serve to assist in resolving complicated ethical problems that affect the care and treatment of patients within healthcare organizations. Just as preventive ethics should be used before an ethical dilemma arises, so should they be used to guide nursing practice before a crisis occurs.

Conclusion

There will always be new ethical dilemmas that require decision-making, and the answers to those dilemmas will not always be obvious or easily identified. It is often in states of uncertainty that serious wrongs occur. As partners in the care of patients and families with advanced illness who must make difficult decisions, nurses must be empowered to facilitate discussion and to be heard by all parties involved. The challenge today is to ensure that all nurses acquire attributes of leadership, excellent communication skills, and self-reflection that enable them to fulfill the crucial role of nursing.

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CHAPTER 71

Palliative Care and Requests for Assistance in Dying

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Key Points

- Assistance in dying is now available in 6 states and the District of Columbia, is being considered in 27 more states, is available with euthanasia in 5 countries, and is available without euthanasia in 3 more countries, making it increasingly likely that palliative clinicians will encounter a request.
- Assistance in dying is highly controversial due to the ethical, legal, and clinical issues it brings to the forefront.
- Although assistance in dying is not a palliative intervention, palliative clinicians are uniquely prepared to field requests without judgment, assess the concerns underlying the request, and ameliorate most of them.

Introduction

Requests for assistance in dying are becoming increasingly common due to legislation in Colorado (2016), California (2015), and the District of Columbia (2016) permitting people with terminal illness to request physician aid in dying (PAD).[1–3] These states join Oregon (1997) and Washington (2009), which enacted Death with Dignity Acts by referendum, followed by Vermont (2013).[2,4,5] In a landmark 2009 ruling, the Montana Supreme Court became the first and only judiciary to authorize physician-assisted suicide by reversing an earlier district court judgment, thus protecting a right to pursue PAD and effectively shielding from prosecution those physicians who choose to honor a person's request.[6] These six states and the District of Columbia make up 16.4% of the US population.[7] Outside the United States, assistance in dying is legal in Canada, the Netherlands, Belgium, Luxembourg, Switzerland, Colombia, and Victoria, Australia. Though highly controversial due to the ethical, legal, and clinical issues it brings to the forefront, it is being debated in 27 other states in 2018. For many nurses, it is only a matter of time before they are confronted with this highly sensitive and personal topic.[8,9]

Assistance in dying is not a palliative intervention. However, Radbruch et al. point out that, "individual requests are complex in origin and may include personal, psychological, spiritual, social, cultural, economic, and demographic factors."[10] Palliative nurses are uniquely trained to assess the hopes, fears, and concerns underlying patient requests for PAD without agenda or judgment. Patients will have individual goals and values deserving of respect, even when they differ from the values of those providing their care. As a result, some may request assistance in dying despite reception of expert palliative care. To ensure palliative specialists are prepared to handle requests for assistance in dying, this chapter will explore the issues and concepts surrounding such requests.

Definitions

The nomenclature surrounding assistance in dying is often value-laden, intended to sway the reader for or against it depending on the perspective with which the author writes. Furthermore, the literature elucidates evolution not only of the nomenclature, but also the underlying philosophy of this topic. Therefore, it is necessary to cite important definitions as a foundation for this chapter.

- *Euthanasia*: A physician (or other person) intentionally kills a person by the administration of drugs at that person's voluntary and competent request.[10]
- *Physician-assisted suicide (PAS)*: A physician intentionally helps a person to terminate his or her life by providing drugs for self-administration at that person's voluntary and competent request.[10]
- *Physician aid in dying (PAD), medical aid in dying (MAD); physician assisted dying*: A physician provides, at the patient's request, a prescription for a lethal dose of medication that the patient can self-administer by ingestion with the explicit intention of ending life.[8]

History

Although legislation and contemporary debate regarding assisted dying and euthanasia have heightened over the past few decades, discussions date back to ancient Greece and Rome, when attitudes toward euthanasia were more tolerant. Medical practice often supported voluntary death requests from patients with intractable suffering, indicating value on the quality of one's life. This contradicted the traditional Christian and Jewish value of life and strict condemnation of suicide in any form as a violation of God's plan and authority. Global consensus opposing assisted death prevailed until the late nineteenth century, when the development of analgesics like morphine marked a pivotal shift in the debate.

Practice changed from prolonging life at any cost to increasing focus on ameliorating suffering and palliation at end of life.[11]

Use of medications to intentionally end life was controversially first proposed in 1870 by Samuel Williams, a nonphysician, thus fueling a global ethics debate. The American Medical Association responded in 1885 with vehement opposition of Williams, likening his proposal to an act of execution.[12] Perspectives shifted again in 1915, when Chicago physician Dr. Harry Haiselden recommended against surgery for a baby boy with severe deformities, thus inciting public discussion on physician responsibility. He argued that infants with severe disabilities were at risk for suffering and could be a potential burden to broader society.[13] In 1906, legislation to legalize euthanasia was defeated in Ohio, followed by defeat of a bill introduced in the British House of Lords in 1936.[14] Throughout the twentieth century, public attitude fluctuated as concurrent global advancement in end-of-life (EOL) care increasingly focused on patient rights and self-determination, bringing right-to-die options to the forefront of a fiercely contested issue.

World View

As of 2016, assisted dying and euthanasia are legal in six countries, and assisted dying without euthanasia is legal in three.[2] The terms "assisted dying" and "euthanasia" will be used separately to distinguish between the two acts. As legislation is introduced worldwide, increased research related to practice, geographic attitudes, and the role of palliative care will occur. Many countries require voluntary consent, mandatory reporting, physician involvement, and a second opinion. These requirements aim to protect against impropriety in euthanasia and assisted death practices. Despite these safeguards, data indicate nonreported or nonconsented cases remain prevalent, which calls into concern potential ethical violations.

Europe is in the vanguard of policy development regarding assisted dying and euthanasia. Swiss law dates to the first federal penal code of 1918 holding that suicide not be considered a crime if motivated by altruistic reasons.[15] In 1942, assisted suicide was decriminalized, although the law does not recognize euthanasia as legal.[16] The law uniquely permits assisted suicide by nonphysicians. Article 115 of the Swiss penal code stipulates that persons assisting suicide are only committing a crime if the motive is selfish and otherwise condones the act for altruistic considerations.[15] Swiss citizens and foreigners need not have a terminal medical condition to request assistance.[10] Due to leniency in foreign participation, Switzerland has seen an influx in "suicide tourism," with increasing requests from visitors with chronic, nonterminal diagnoses.[17]

Elsewhere in Europe, assisted dying was legalized in the Netherlands (2001), Belgium (2002), and Luxembourg (2009).[10] Legalization of euthanasia and assisted suicide was sanctioned in the Netherlands through the Termination of Life on Request and Assisted Suicide Act. Minors, aged 12–16, can also access the law if the requirement for obtaining parental consent is met.[10] There is also consideration for people with dementia.[18] Data from 2014 showed that patients in the Netherlands requesting euthanasia or assisted dying accounted for less than 4% of total deaths and for around 4.5% in Belgium.[16] Increased percentages of euthanasia over assisted suicide in countries where both are legal postulate a preference for patients to have providers perform the procedure when given a choice.[19]

Belgium legalized euthanasia in 2002 as a voluntary act by lethal injection for patients with similar qualifications as the Netherlands. The condition need not be "terminal," but additional process and time requirements are imposed if the person is not terminally ill. The law was extended in 2014 to include minors with parental consent and in certain cases when criteria is met for patients with mental suffering.[18] This accounts for a small percentage of total reported cases.[20] Case totality increased significantly between 2007 and 2013, from 1.9% to 4.6% of deaths. Palliative services were provided concurrently in 73.7% of cases in 2013.[21] A comparison of palliative development between 2005 and 2012 in the Benelux countries, where assisted dying is legal versus those where it is not permitted showed that, despite theories that palliative development would be stunted, services and spending expanded.[22]

In 2015, the European Association for Palliative Care (EAPC) published a follow-up white paper on assisted dying/euthanasia to provide an ethical framework for the palliative care field.[10] The paper supported palliative care involvement for people considering assisted dying/euthanasia, yet stipulated that the practice should not be a part of palliative care.[10] The paper refocused core palliative care tenets as a benefit to comprehensively assess and understand the rationale behind an individual requesting assisted dying.[10]

Canada legalized euthanasia and assisted dying in 2015, via unanimous decision by the Supreme Court of Canada (*Carter v. Canada*), which followed years of consideration by parliament (aside from Quebec, which passed legislation in 2014). The court ruled that prohibition of assisted dying was in violation of the Canadian Charter of Rights and Freedoms and spurred legislative development to support assisted dying.[21] Eligibility criteria include mental capacity, voluntary request, and a "grievous and irremediable medical condition" that causes intolerable suffering. Canadians overwhelmingly supported the ruling, with 78% of those polled in agreement.[23] Canadian law also broadens the role of medical providers who can provide care to include both physicians and nurse practitioners in certain provinces.[24]

In 2015, the Colombian Ministry of Health formalized the process for euthanasia. The Colombian Constitutional Court initially permitted mercy homicide in 1997, but took almost two decades to develop specific instructions on how the process could take place.[18] Australia passed legislation in 1996 legalizing both assisted dying and euthanasia in the Northern Territory. It was overturned the following year by Parliament.[10] In late 2017, the Australian state of Victoria passed legislation legalizing assisted dying.[25]

United States

The movement toward assisted dying has gained momentum in the United States following inception of Oregon's Death with Dignity Act (1994), with 51% of voters in favor of the law. Implementation was delayed by legal injunction until 1997, when voters again retained the act with approval of 60%.[26] Passage demonstrated a landmark change in attitude and legislation regarding the "right to die" debate in the United States. At that time, the US Supreme Court ruled that PAD should be determined at a state level.[27] Prescriptions are permitted based on safeguard criteria allowing adults with mental capacity who have a prognosis of 6 months or less to provide informed and voluntary consent. Moreover, consultation with a second medical provider is required, and follow-up with mental health professionals is recommended if there are concerns of psychological or psychiatric disorders.[18]

Brittany Maynard, a 29-year-old volunteer in a national right-to-choose advocacy organization who suffered from terminal cancer, brought EOL discussions into the national spotlight in 2014, when she moved from California to Oregon for access to assisted dying. Her movement sparked controversy and brought a new perspective to a contentious issue that had been primarily associated with the elderly.[28]

Hospice is commonly provided concurrently to patients who utilize assisted dying. Reports from 2009–2011 demonstrated that in Oregon 96% and in Washington 81% of patients received hospice. As of 2017, 1,749 prescriptions were written, and 1,127 people died from ingestion since initiation of the law. This accounted for 37.2 per 10,000 total deaths in 2016.[4] The state of Washington (2015) reported 938 prescriptions and 917 deaths since 2009.[5] Numerous states have assisted dying legislation pending, and public debate continues on the legal and ethical implications of PAD.

Ethics

The ethical deliberations encompassing PAD are based predominantly on the four pillars of medical ethics: autonomy, beneficence, nonmaleficence, and justice.[29] *Autonomy* in medical decision-making can be defined as a patient's ability to make independent decisions related to his or her well-being.[30–32] Often, this is further defined as a patient's ability to make a decision without coercion or untreated mental illness and with the ability to rationalize a decision.[33] This is the foremost ethical concept supporting PAD requests. It is essential to ensure the patient's autonomy in relation to his or her decision to request aid in dying.[34] There are a number of threats to autonomy, including but not limited to metabolic disturbances, brain metastasis, unmanaged symptom burden, and poorly understood complex care plans. In addition, religious influence and family perception of the medical situation affect decisions around PAD.[35] Family beliefs can guide patients to make a decision contradicting their personal choices. If care decisions are made based on family preference, autonomy may be sacrificed.[36] This warrants consideration at end of life; however, there is currently little impact around PAD because of the requirement of capacity and the inability of surrogate decision-makers to elect PAD on behalf of their loved one in most locales.[37]

The autonomy of the care team is also valued. The nurse may object to participation in what he or she views as the termination of a patient's life and should have the right to do so.[21] Conscientious objection can also be found among other care team members and, if encountered, should be respected.[38] Transfer of care to other staff should be encouraged.

Beneficence is benefit to the patient, which in PAD is a major point of contention.[29] Proponents argue that PAD is beneficial to the individual with a terminal disease by allowing the patient control of his or her dying process, hence preventing degradation of quality of life (QOL). Opponents argue that improved medical technologies such as palliative surgery, radiation, or medication management could provide improved QOL. Furthermore, they posit that the availability and engagement of palliative and hospice care invalidates the benefit of PAD. The palliative care and hospice healthcare team provide the standard of care during terminal illness and are recognized as experts in symptom management, with the primary focus on improving QOL. It is important to recognize that where PAD has been legalized, the prevailing view of the legal system and public opinion are that PAD provides benefit to the patient.[21,31,39]

Nonmaleficence means "first do no harm," another source of debate regarding PAD.[29] Supporters indicate that, by respecting autonomy, the patient dictates his or her own medical course and decline, choosing the time of death in relation to the disease process. PAD prevents the patient from being harmed by uncontrolled or underaddressed symptoms while avoiding prolonged suffering and loss of dignity or respect. Opponents argue that PAD brings harm by ending life, potentially depriving people of valuable experiences that illness may bring, both personally and with loved ones.

Justice is viewed as providing what is fair and equitable to a patient.[29] This can be viewed on an individual level as related to patient choice or on a systems level based on resources available. The issue of justice is partially addressed in states and countries where PAD is legal by making it available to all residents. Unfortunately, socioeconomic status may preclude some from accessing PAD due to the exorbitant cost of filling certain prescriptions. In addition, PAD is not available in every state, and residency requirements restrict those from requesting it who do not live within the jurisdiction in which it is legal.

Another concern about justice described in the literature is that physicians are providing EOL care and, at times, hastening the end of life of patients who, in their view, are suffering.[35] Timothy Quill, in his writing on "The Graying of America," argues this point: whether through withdrawal of treatments, failure to offer treatments, or adjustment of medications with the understanding of the dual effect of these medications with palliative intent, he believes that hastening of death is occurring, although it appears to be "unevenly and unpredictably available."[40] Quill supports legalization of PAD and making it available to all only after expert palliative care has been obtained and patients have failed to respond adequately with treatment.[40] A study completed in European intensive care units indicated that physicians caring for patients who had treatments withdrawn would intentionally accelerate the dying process in up to 18% of cases. While this supports Quill's concern regarding the justice of PAD, it also demonstrates the concept of double effect. While these clinicians were attempting to alleviate symptoms, they accelerated the patient's death.[35]

Autonomy, beneficence, nonmaleficence, and justice, however, cannot be applied to a question without considering the surrounding context. For example, the question is "Should physicians be allowed to assist patients with dying?" Traditionalists would argue that the Hippocratic Oath defines and limits the physician role to that of healing and curing disease while bringing no harm.[35] Without context, the immediate morally intuitive response would be "no"; however, when the context of the question is defined, then the ethics considerations become more complex.[31] Asking whether physicians should be allowed to assist patients with terminal illness who are at risk for unbearable suffering to die comfortably and with dignity may lead to a more robust conversation and perhaps a different outcome.

Throughout the medical and legal literature related to PAD, the terms "suffering" and "dignity" are often referenced.[34,41,42] Each individual is responsible for defining what suffering and dignity mean, and these definitions underlie an individual's narrative and therefore cannot be interpreted by another without exploring the individual's definitions.[32,42,43] For the sake of this discussion, we will discuss and define these terms based on current literature.

There are various types of suffering—physical, emotional, and spiritual, with the latter two characterized as existential.[41,44] Physical suffering is addressed with direct management of the identified source of suffering. For example, mixed pain with bone and nerve components secondary to compression fracture may be treated with analgesics and/or kyphoplasty. Existential suffering, on the other hand, can lead to significant treatment challenges due in part to a lack of training for providers.[44] Existential suffering may include but is not limited to loss of dignity, purpose, or meaning. There are validated screening tools available to assist the medical team in this area. Unfortunately, the resources allocated to the treatment of existential suffering are often overtasked and understaffed, thus highlighting the importance of a team approach versus an individual one. The palliative care interdisciplinary team will focus on emotional, social, physical, and spiritual aspects of suffering, otherwise known as *total pain*, and treat them accordingly.

The palliative provider will strive to understand the person's individual narrative and how it can modify how he or she relates to or defines suffering.[32] One's narrative is not only generated individually, but is shaped by surrounding influences. In the past, the question was asked whether those who pursue PAD are doing so secondary to depression. Today, it is fair to consider whether it represents an autonomous choice to forego living with a disease and its burden. If one demonstrates the ability to understand a disease and its outcome and can rationalize the result of one's action independently and without coercion, this may be considered a valid decision.[33,45,46]

Like suffering, dignity is inherent to the topic of PAD. Soren Holm, in "Undignified Arguments," notes the frequent use of the term in the medical, ethical, and legal literature, as well as in rulings associated with medical cases.[21,32,34,47] Dignity often relates to the ethical principle of autonomy, which is a direct reflection of an individual's choices. This may be subdivided to include inherited dignity (being a human being) and personal dignity, as well as identifying key areas of focus for dignity, including respect, spiritual peace, and hope.[32,48] The patient is not the only one experiencing the dying process. Family, friends, and the healthcare team of the patient will also perceive the event through the lens of their own individual influences, each determining whether it was a dignified death. Whether PAD is applied or not, it is vital to understand the individual's values and beliefs that inform treatment. Consideration should be given to involving palliative care or hospice, usually well-equipped both in training and skills, to meet the needs and goals of the patient and family.

Informed consent in PAD is also an area of concern. Informed consent, including for alternatives, must exist if the patient is to exercise autonomous decision-making in treatment choices.[37,40] As the complexity of treatment plans increase, the issue of what the patient understands about treatment is often less clear.[43] Within each locality where PAD is legal, there are various criteria in place, including second opinions, psychiatric evaluation, and documentation of the ability to rationalize the choice, to ensure that the patient is fully capable of consent and fully understands what is being requested.[21] There has been concern around ensuring that these criteria are being met and true informed consent is obtained.

Legal

One of the first legal cases bringing attention to QOL issues and prolonged dying was the Karen Ann Quinlan case in the 1970s, which became an impetus for discussion around PAD and withdrawal of life-prolonging interventions. From there, a number of subsequent treatments that prolonged life began to be addressed.[31] Several cases have been heard by the US Supreme Court, with favorable rulings for patients' or surrogates' right to refuse life-sustaining therapies as well as the state's rights to individually address issues of PAD.[31,49] Today, these questions continue to be encountered, particularly in the presence of advancing technologies. Although less litigious, these questions become the charge of local palliative care or ethics teams to address within healthcare systems.

The legalization of PAD has been accompanied by safeguards to prevent potential misuse of the laws and to protect not only patients but also providers. There are concerns that some of the safeguards are not being monitored or enforced with regularity and that the procedure of PAD is being carried out in violation of acceptable standards of care. The *Michigan Law Review* completed a medical review of the Oregon PAD program and found that compliance with the Death with Dignity Act was not being followed and therefore that it was not possible to ensure that safety guidelines were enforced.[50] This substantiates the concern for a "slippery slope."[19,35] These safeguards to define the procedural component of PAD did not address clinical criteria for its use. Medical experts, including supportive services, came together to define clinical guidelines and criteria for PAD.[37] The most recent revision of criteria was completed in 2012, with the formation of the Physician Aid in Dying Committee. By ensuring that safeguards and defined clinical criteria are followed, it is possible to protect both the patient and provider.

Continued high visibility around the issue of PAD has resulted in a rapid acceleration of attempts and successes in introducing legislation at the state level.[49] This is being driven by public opinion and awareness, as well as by legal action.[21,39,43,51] A majority of the state laws being passed—and, in fact, country laws in the case of socialized medicine—are the result of legal action.[39,52]

Case Study: A Patient Requesting Physician Aid in Dying

Kathy, a 68-year-old married female, was diagnosed with metastatic ovarian cancer 3 years ago. She held a master's degree and owned an art and dance studio. She completed standard treatment for her cancer followed by a clinical trial, but she developed disease progression leading to recurrent partial bowel obstructions and generalized edema rendering her bedbound. Kathy was recently rehospitalized with a recurrent bowel obstruction.

She and her husband met with the palliative care team. During the initial consultation, she inquired about the physician aid in dying (PAD) process. With her husband at her side, she was very calm and rational as she discussed this option, explaining why PAD appealed to her. She shared that she had lost control and noted the lack of further disease-modifying treatment options making a further decline and death inevitable. She worried that she was only prolonging the burden of caring for her and did not see a purpose in continuing to live with a progressive decline. She reminded us that PAD had been on her mind for the past 3 years and that, now that this choice was legal in her state of residence, she wanted to proceed with this option.

Characteristics of Those Who Request PAD

Most who request PAD are individuals who are facing a life-limiting situation. A conversation may be initiated by a patient shortly after hearing the news of having a limited prognosis, sometimes as short as weeks or days. Requests for information about PAD may occur for several reasons including but not limited to curiosity, contingency planning, and fear of lingering or suffering. Requests may also be made as a planning measure to ensure control and provide options for individuals with terminal illness who are fearful of potential physical or emotional suffering. Finally, other requests are carried out with the intent to move forward with PAD.

A 2003 study of physician descriptions of patients requesting PAD found that the majority were nearing end of life and suffered a high degree of pain or symptom burden.[53] Patients making requests were primarily male, between 46 and 75 years old, and of European descent, and approximately half had a terminal cancer diagnosis.[53] Similarly, data from Oregon show patient characteristics as aged 65 years or older, white male, college-educated, and with a cancer diagnosis.[54] Reasons cited for the request included loss of autonomy (93%), diminished ability to participate in activities that bring joy (88.7%), and loss of dignity (73.2%).[54] A retrospective study of experiences of families of patients in Switzerland cared for by a palliative team who died after assisted suicide found that existential distress and fear of loss of control were predominant reasons for the request.[55]

Responding to Requests

Regardless of a provider's personal position or whether it is legal within the jurisdiction in which the interaction occurs, it is vital for the provider to listen to the patient without judgment while offering support.[56] Exploration of the hopes, worries, and concerns of the patient will assist in clarifying the intent of the request while identifying opportunities for palliative intervention with the goal of relieving distress. Providers who are willing to listen to the patient and openly discuss the option of PAD denote respect, thus fostering a therapeutic relationship between the provider and patient at a critical juncture.[56]

The conversation will offer insight into whether the patient possesses decision-making capacity, is adversely affected by psychiatric illness, or is suffering emotional distress, thus allowing for screening and appropriate referral to a mental health professional when appropriate.[50,51] Finally, the provider should attempt to ascertain how the request correlates with the patient's goals and values.[56] Consistency over time may lend credence to a request whereas inconsistency may alert the clinician to the need to further explore the request.

Alternatives to Physician Assistance in Dying

Patients who request PAD may recognize barriers blocking access to PAD. Some barriers may include but are not limited to locating a prescriber, enduring the 2- to 3-week time period required by law, insufficient finances to purchase the medications, and lack of family support. As a result, patients may need to consider alternative options to allow for a more natural dying process. It is possible to meet most patients' needs, resulting in a natural death rather than utilization of PAD.[40]

Various alternatives include the right to refuse or withdraw treatments. For example, a patient with myelodysplastic syndrome converting to acute myeloid leukemia who is transfusion-dependent may opt to forego further transfusions. In cases during which the patient demonstrates refractory symptoms creating uncontrolled suffering, palliative sedation may be employed. This procedure titrates sedation to symptom relief.[57] Some view this as the most intense method of symptom management, carrying with it the recognition that it truly represents the end of the patient's life unless it is utilized for respite.[58] Finally, voluntary stopping of eating or drinking (VSED) is an alternative that is gaining more attention in the literature. This method allows the patient to stop consuming any food or fluids in order to hasten death.

In all aforementioned situations, patients with a prognosis of 6 months or less may benefit from hospice care. Hospice offers supportive assistance and should be encouraged for every person facing the end of life, whether the patient chooses PAD or not. The hospice team provides the highest quality of pain and symptom management with a focus on the social, emotional, spiritual, and physical aspects that may improve the patient's QOL while allowing the natural failure of the body from disease.[59] The benefit also offers 13 months of bereavement care to the family, thus allowing for grief support.

Conclusion

PAD is a controversial subject encompassing clinical, legal, and ethical issues. Though not a palliative intervention, palliative clinicians are uniquely prepared to assess the multiple sources of physical and existential suffering that lead to its consideration, thus leading to appropriate treatment resulting in improved QOL. Some, however, may not be palliated despite expert intervention or may consider PAD for personal reasons. They may also benefit from consideration of palliative consultation as a means of exploring their options without judgment or agenda and with empathy and kindness.

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CHAPTER 72

Nursing Education

Pam Malloy and Andra Davis

Key Points

- There is a need for palliative care nursing education.
- Practice guidelines and competencies for palliative care provide direction for nursing faculty, students, and practicing nurses.
- Updates to prelicensure education and changes in advanced practice registered nursing (APRN) will promote improved palliative care.

Introduction

There has never been a more exciting time to be a nursing educator, promoting palliative care education, practice, policy, advocacy, and research. Opportunities are unprecedented to provide this education to the next generation of nurses, as well as to clinicians, educators, and researchers. The National Institute of Nursing Research (NINR) included end-of-life (EOL) and palliative care in its strategic plan and noted that this care is truly a "science of compassion."[1] This inclusion aligns with the core of nursing practice: contribute to, organize, implement, and assess the interprofessional plan of care for those with serious, complex illness/injury in clinics, acute care facilities, and community settings. Nurses play a key role in providing holistic palliative care to those with serious illness because they recognize it is "fundamental to health and human dignity and is a basic human right."[2]

Nurse educators and leaders promote standards of palliative care, supporting healthcare systems to integrate this care throughout community settings. While hospitals provide care to the sickest, the majority of those with serious illness are generally at home, "neither dying nor in the hospital."[3] Numerous documents from national and international organizations provide position statements, standards, and guidelines for promoting excellent palliative care education.[1, 3–10] Students' clinical experiences and didactic instruction are often based on a curative-oriented perspective. Nursing faculty have a responsibility to integrate palliative care principles into both the classroom and clinical arenas, enabling students to learn and practice comfort-oriented care and communication as equally important nursing competencies. Future employers will demand they have this expertise. With the *Competencies and Recommendations for Educating Nursing Students* (CARES) document, nursing faculty has a blueprint of necessary entry-level competencies.[5]

Today, more than 90% of hospitals with 300 beds or more provide palliative care services.[11] The Joint Commission is now recognizing the importance of palliative care in the healthcare system and is promoting opportunities for hospitals to obtain Advanced Certification in Palliative Care.[12] Because of the increased focus on palliative care and growing numbers of palliative care teams there is a continuing need and commitment to promote and provide such nursing education.

While a variety of healthcare providers care for patients and their families from the time of diagnosis of a serious illness through the end of life, nurses are the constant presence and spend the majority of time listening, bearing witness, facilitating patient-directed goals, coordinating, and implementing care. Just as education is vital to safely bringing new life into the world, it is equally critical to commit to education and experiences that promote holistic, compassionate, and sacred care for those at the end of their lives. Therefore, palliative care education should begin at the entry-to-practice level; extend to advanced, specialty nursing practice; and be available for practicing nurses through clinical in-services, continuing education courses, annual competencies, and professional conferences.

History of Palliative Care Nursing Education

Nurses have a long history of leading the efforts in developing policies and guidelines regarding palliative care. Leading the way were visionaries such as Dame Cicely Saunders, who began her career as a nurse and went on to found the first free-standing hospice in London, England, in 1967. Following in 1974, the first US hospice was founded by Florence Wald. Jeanne Quint Benoliel examined the nurse's role in caring for the seriously ill from a psychosocial standpoint with her research, directing healthcare providers to include families in decision-making and caregiving.[13,14] The American Association of Hospice and Palliative Medicine (AAHPM) included several nurses in its first cohort of visionaries, recognized as being among the most influential leaders in hospice and palliative care. Serving their profession for at least 25 years as leaders in palliative care, these nurses included Nessa Coyle, PhD, ANP, FAAN; Patrick Coyne, MSN, APRN, ACHPN, FPCN FAAN; Betty Ferrell, PhD, RN, MA, CHPN, FPCN, FAAN; Sister Mary Giovanni, RN; and Nancy Hinds, RN.[15]

These visionaries have been role models, particularly in education. Faculty cannot teach and nurses cannot practice what they do not know. Because of long-standing gaps in EOL content in curricula, nurses practiced with limited knowledge of how to attend to the suffering of patients and their families facing EOL issues.[16]

A chain of events began with the 1998 publication of the American Association of Colleges of Nursing's (AACN) *Peaceful Death* document. This document outlined 15 palliative care nursing competencies and was followed by a ground-breaking review of nursing school curricula that confirmed the severe paucity of palliative and EOL care concepts.[17,18] An early analysis of nursing textbooks revealed that only 2% of overall content was related to EOL care, and much of the information was inaccurate and/or outdated.[18] Pain and symptom management were virtually absent, and information about communication at the end of life was also lacking. There was minimal information about the roles and needs of family caregivers and issues of policy, advocacy, ethics, and law, as well as scarce information about death awareness, anxiety, imminent death, and preparation of families for the death. Grief was described, but there was little information about nursing interventions or the nurse's personal experience of loss. Pharmacological information was either mentioned briefly or absent.[18] Graduate nursing faculty also reported, in a 2006 research survey, that although they believed EOL education was important, they saw their own programs being only moderately effective in promoting and providing the content.[19] With the development and dissemination of the End-of-Life Nursing Education Consortium (ELNEC) advanced practice registered nurse (APRN) curriculum in 2013, practicing APRNs can now receive further education as they begin or continue to practice palliative care, and graduate nursing faculty can obtain resources to embed in master's and doctoral nursing programs.[20]

Other opportunities to promote palliative nursing education involved collaborating with the National Council of State Boards of Nursing (NCSBN) to improve EOL content in the national nursing licensure examination for registered nurses (NCLEX-RN).[21] NCLEX began incorporating EOL issues beginning in 2001, resulting in an increase in evidence-based practice and the expansion of EOL and palliative care. The *Peaceful Death* document was updated and expanded in 2016, and is known as the CARES document.[5]

These efforts have increased palliative care content in nursing curricula, culminating in 2017 with a call to action released jointly by the American Nurses Association (ANA) and Hospice and Palliative Nurses Association (HPNA) recommending that nurses lead and transform palliative care.[22] In this directive, ANA president Pamela F. Cipriano called for every level of nurse to "have the knowledge and ability to facilitate healing and alleviate suffering through the delivery of safe, quality, and holistic, person-centered, primary palliative care."[22(para 2)] First among the 12 recommendations is the standard use of the ELNEC curricula available for general and specialty practice, as well as the recently released online undergraduate modules.[23]

Curriculum Developed to Assist Nurse Educators

Nursing faculty, continuing education (CE) providers, and staff development educators (SDEs) have long looked to the ELNEC curriculum, originally funded by the Robert Wood Johnson Foundation (RWJF) in 2000, as the primary evidence-based curriculum to teach the next generation and practicing nurses about this vital care.[16,18,24,25] The curriculum, updated annually since ELNEC-Core debuted in 2001, centers around eight content areas listed in Table 72.1. Education is provided through lectures, case study reviews, role plays, and videos. Individuals attending the ELNEC course learn content and obtain skills to teach that content. Since its inception, ELNEC has broadened both in scope of specialty content and international adaptation. Table 72.2 summarizes various curricula that have evolved since 2000.

More than 1,600 nurses attended one of the first eight RWJF-funded ELNEC train-the-trainer courses and reported 1-year post-course that they had provided ELNEC training to more than 19,000 student nurses. Forty-nine percent of the CE providers and SDEs stated that they were able to disseminate ELNEC-Core to clinical settings and CE programs throughout their community.[26,27] These data reflected successful adaptation across many settings. Several factors contribute to this effective dissemination: nursing faculty had long cited difficulty in adding new content to an already robust curriculum; and CE providers and SDEs are responsible for maintaining and addressing quality improvement issues, orienting new staff, often overseeing nursing internships/residency programs, providing CEs, preparing for Joint Commission visits, maintaining Magnet status, and attending to annual competencies. Each of these was an opportunity to promote palliative care education.

The ELNEC project continues to provide annual national and international train-the-trainer courses. The most recent figures reflect continued momentum and expansion, with 214 ELNEC

Table 72.1 End-of-Life Nursing Education (ELNEC)—Core Consortium modules

Module	Description of content
1. Introduction to Palliative Nursing	Creates an overview of the need to improve palliative care and the role of the nurse as a member of an interdisciplinary team in providing quality care.
2. Pain Management	Reviews basic principles of pain assessment and management in patients with serious illness/injury.
3. Symptom Management	Builds on Module 2: Pain Management, by addressing other symptoms common in advanced disease and the role of the nurse in managing these symptoms.
4. Ethical/Legal Issues	Discusses key ethical issues and legal concerns in palliative care and resources to address these in practice.
5. Cultural/Spiritual Considerations	Reviews dimensions of culture, which influence care in advanced disease.
6. Communication	Emphasizes the importance of good communication in palliative care and provides "the words" to improve care.
7. Loss/Grief/Bereavement	Addresses the challenging aspects of grief, loss, and bereavement of patients and families as well as the loss experiences of nurses.
8. Final Hours	Focuses on care at the actual time of death, emphasizing the preparation necessary to insure the best care at this critical event.

Source: End-of-Life Nursing Education Consortium (ELNEC)—Core Curriculum. American Association of Colleges of Nursing (AACN), Washington, DC and City of Hope, Duarte, CA.

Table 72.2 Various ELNEC curricula developed

ELNEC curricula/date of presentations	Overview of participants	Funder
Current Curricula		
ELNEC-Core (2001–Present)	Staff nurses, APRNs, nursing students and faculty, staff development educators, unit-specific educators, community educators, administrators, researchers who work in acute care settings (i.e. medical-surgical and oncology units, clinics, homecare, hospice and palliative care settings)	RWJF, 2000–2004 Stupski Foundation (2016–2017)
ELNEC-Pediatric Palliative Care (2003–Present)	Nurses described in ELNEC-Core are also targeted for this course. Those working in pediatric units, pediatric (PICU) and neonatal intensive care units (NICU), hospice, homecare, clinics, and schools	Aetna Foundation (2005–2006)
ELNEC-Critical Care (2006–Present)	Those working in intensive care (ICU), coronary care (CCU), burn, dialysis, transplant units, emergency departments, etc	Archstone Foundation (2007–2010) Milbank Foundation (2014–2016)
ELNEC-Geriatric (2006–Present)	Geriatric nurses working in long-term care and skilled nursing facilities, nursing homes, undergraduate and graduate nursing faculty, hospice, community, and acute care nurses	California HealthCare Foundation (2008–2010)
ELNEC-APRN (2013–Present)	APRN nurses with 2 tracks to choose from: Adult and pediatric tracks	Cambia Health Foundation (2012–Present) Milbank Foundation (2014–2016)
ELNEC-International (2006–Present)	Presented in 96 countries worldwide to nurses and other interdisciplinary team members.	Open Society Foundations (2005–2017) Oncology Nursing Foundation (2013) American Association of Colleges of Nursing (AACN) (2015)
ELNEC-Undergraduate (2017– Present)	This online, interactive palliative care curriculum, is designed to meet the recommendations of the 2016 document and assists nursing students to successfully meet the 17 competencies and nurse residency programs, as they enter practice.	Cambia Health Foundation (2017–2019)
ELNEC-Oncology APRN (2017–Present)	Oncology APRNs to be prepared as generalists in palliative care.	National Cancer Institute (NCI) (2017–2022)
Integrating Palliative Oncology Care into Doctor of Nursing Practice Programs (2013–2018)	Doctor of Nursing Practice (DNP) faculty in an effort to integrate palliative care content into DNP program curricula.	National Cancer Institute (NCI) (2013–2018)
Past Curricula		
ELNEC-For Veterans (2009–2012)* ELNEC-For Veterans/Critical Care (2012) ELNEC-For Veterans (2017)	Nurses who work in Veteran-specific facilities, representing over 200 institutions **Note*: This 2017 curriculum is available on-line at no cost at https://www.wehonorveterans.org/elnec-%E2%80%93-veterans-updated-curriculum	The US Department of Veterans Affairs (2009–2012) Milbank Foundation (2012)
ELNEC-For Public Hospitals (2011–2013)	This course was presented to nurses in 16 public hospitals throughout California in November, 2008.	The California HealthCare Foundation (2011–2013)
ELNEC-Oncology (2003–2007)	Nurses belonging to an Oncology Nursing Society (ONS) chapter, working in inpatient, outpatient bone marrow transplant settings	National Cancer Institute (NCI) (2003–2007)
ELNEC-Graduate	Graduate nursing faculty in Schools of Nursing throughout the US	National Cancer Institute (NCI) (2003–2007)
TOTALS = 13 curricula		11 Funding Sources

train-the-trainer courses held nationally and internationally in the first 17 years of the project, with more than 22,300 educators completing the curricula and returning to their communities to provide ELNEC education to more than 668,000 healthcare professionals.[28]

One of the most recent expansions of the ELNEC curricula, ELNEC-Undergraduate, addresses the scarcity of undergraduate nursing education in palliative care.[18,29] In 2015, funded by Cambia Health Foundation, the ELNEC project assessed the current state of palliative care education in undergraduate nursing programs and began to develop an online prelicensure ELNEC curriculum. Using the original 1998 EOL competencies and the *Peaceful Death* document as a template, the new *Competencies and Recommendations for Educating Undergraduate Nursing Students* (CARES) was developed and unanimously approved by AACN in 2016.[5] CARES summarizes the educational needs of nursing programs, makes recommendations for how to incorporate the competencies in core nursing courses, and lists the 17 competencies needed for all students to achieve by graduation.[5] Box 72.1 lists these competencies.

Box 72.1 New Competencies for Educating Undergraduate Nursing Students to Improve Palliative Care

Competencies that new nurses need to have completed by the end of their undergraduate nursing education are the following:

1. Promote the need for palliative care for seriously ill patients and their families from the time of diagnosis as essential to quality care and an integral component of nursing care.
2. Identify the dynamic changes in population demographics, healthcare economics, service delivery, caregiving demands, and financial impact of serious illness on the patient and family that necessitate improved professional preparation for palliative care.
3. Recognize one's own ethical, cultural, and spiritual values and beliefs about serious illness and death.
4. Demonstrate respect for cultural, spiritual, and other forms of diversity for patients and their families in the provision of palliative care services.
5. Educate and communicate effectively and compassionately with the patient, family, healthcare team members, and the public about palliative care issues.
6. Collaborate with members of the interprofessional team to improve palliative care for patients with serious illness, to enhance the experience and outcomes from palliative care for patients and their families, and to ensure coordinated and efficient palliative care for the benefit of communities.
7. Elicit and demonstrate respect for the patient and family values, preferences, goals of care, and shared decision-making during serious illness and at end of life.
8. Apply ethical principles in the care of patients with serious illness and their families.
9. Know, apply, and effectively communicate current state and federal legal guidelines relevant to the care of patients with serious illness and their families.
10. Perform a comprehensive assessment of pain and symptoms common in serious illness, using valid, standardized assessment tools and strong interviewing and clinical examination skills.
11. Analyze and communicate with the interprofessional team in planning and intervening in pain and symptom management using evidence-based pharmacologic and nonpharmacologic approaches.
12. Assess, plan, and treat patients' physical, psychological, social, and spiritual needs to improve QOL for patients with serious illness and their families.
13. Evaluate patient and family outcomes from palliative care within the context of patient goals of care, national quality standards, and value.
14. Provide competent, compassionate, and culturally sensitive care for patients and their families at the time of diagnosis of a serious illness through the end of life.
15. Implement self-care strategies to support coping with suffering, loss, moral distress, and compassion fatigue.
16. Assist the patient, family, informal caregivers, and professional colleagues to cope with and build resilience for dealing with suffering, grief, loss, and bereavement associated with serious illness.
17. Recognize the need to seek consultation (i.e., from advanced practice nursing specialists, specialty palliative care teams, ethics consultants, etc.) for complex patient and family needs.

Source: American Association of Colleges of Nursing (AACN). CARES: competencies and recommendations for educating undergraduate nursing students: preparing nurses to care for the seriously ill and their families. http://www.aacnnursing.org/Portals/42/ELNEC/PDF/New-Palliative-Care-Competencies.pdf. Published February 2016. Accessed October 3, 2017.

In January 2017, ELNEC-Undergraduate was released online through Relias, a comprehensive, innovative service that addresses the educational needs of nurses in a variety of clinical settings. ELNEC-Undergraduate is intended to assist faculty in meeting the required competencies. The curriculum consists of six, 1-hour, interactive, online modules modeled after the ELNEC-Core modules, with Cultural/Spiritual Considerations and Ethical/Legal Aspects of Care embedded in each of the six modules. The curriculum can be used across a variety of courses or as a stand-alone course and will revolutionize undergraduate preparation in palliative care. Each module permits students not only to read text, but also to hear from national palliative care leaders, to review case studies, and to view communication vignettes. Multiple-choice questions at the end of each module are designed to provide an opportunity to evaluate learning and allow students opportunities to practice taking NCLEX-style questions. In the first 10 months since its inception, more than 100 schools of nursing across the nation had signed up more than 5,000 students to review the curricula. For more information about ELNEC-Undergraduate, visit http://elnec.academy.reliaslearning.com/.

Other ELNEC curricula are also available online through Relias. Through an online subscription, Relias administers not only

ELNEC-Undergraduate, but also Core, Pediatric Palliative Care, Geriatric, and Critical Care. Each curriculum includes vignettes and other useful resources to improve nursing education. For more information on online ELNEC curricula, visit https://www.reliaslearning.com/elnec.

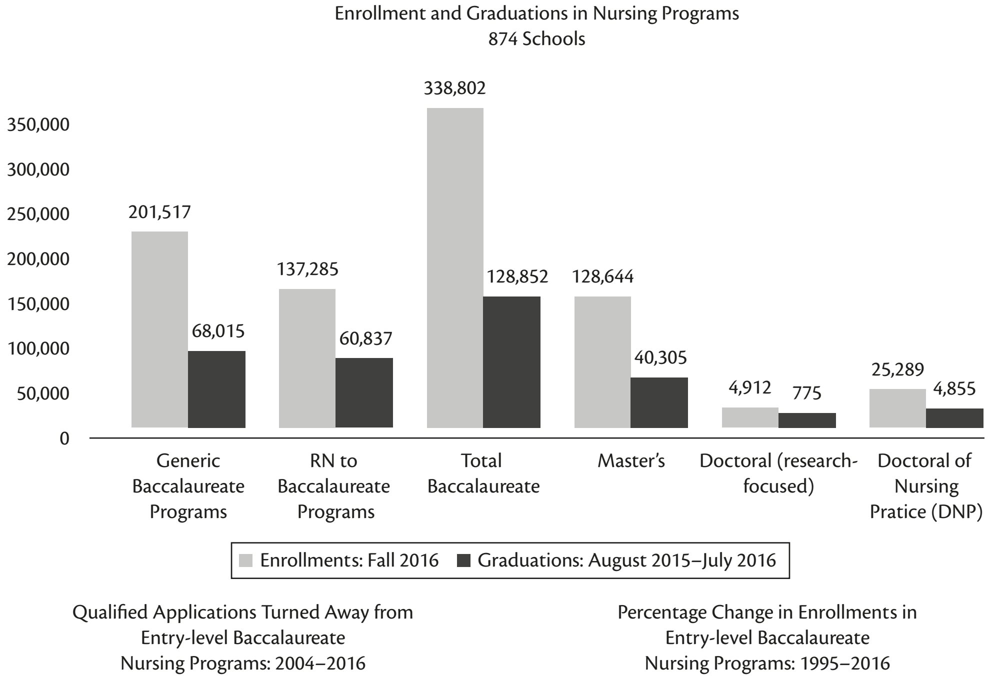
Barriers and Opportunities for Palliative Care Nursing Practice and Education

Both barriers and opportunities exist today in providing palliative care and in promoting the education required to implement that care. For example, one of the leading barriers that nurses face today are laws in many states that prohibit and prevent APRNs from practicing to the full extent of their education.[30] For nurse educators, barriers include lack of time to teach palliative care principles in an already overcrowded curriculum and lack of palliative care expertise among the faculty.[26,31–34] Nurse educators, administrators, and national organizations must be on the forefront to advocate the elimination of these practice and educational barriers so that these well-educated nurses can contribute their talents to meeting the healthcare needs of the nation. Schools of nursing must be committed to providing more generalist versus specialist education, and a greater emphasis needs to be placed on delivering care in the community rather than in acute care settings alone.[35]

Currently, the NCSBN has an initiative to assist in breaking down some of these barriers by supporting states in aligning APRN regulations with the Consensus Model for APRN Regulations. *APRN Campaign for Consensus: Moving Toward Uniformity in State Laws* promotes elements supporting the four roles of advanced practice (certified nurse specialist [CNS], certified nurse practitioner [CNP], certified registered nurse anesthetist [CRNA], certified nurse midwife [CNM]).[36]

Now that barriers have been removed in some states, nurses across the nation have a renewed interest in opportunities to advance their education—whether in obtaining their baccalaureate or graduate degree.[37] Nurses have many options for furthering their education on the graduate level (i.e., Clinical Nurse Leader [CNL], Masters of Science in Nursing [MSN], Doctor of Nursing Practice [DNP], Doctor of Philosophy [PhD], Doctor of Nursing Science [DNS/DNSc]). The demand for doctoral nursing education is growing rapidly in the United States. According to the AACN's 2016–2017 annual survey, which showcases 874/980 (89.2%) nursing programs in the United States, enrollment at the master's, research doctorate (PhD, DNSc, DNS), and doctor of nursing practice (DNP) levels were 128,644, 4,912, and 25,289, respectively.[37] Growth in baccalaureate, master's, and doctoral enrollments and graduations continue to rise (Figure 72.1).

While nurses remain committed to seeking further education, the United States continues to grapple with its complex healthcare system. Nurses have to be informed about professional issues, including political ones, and rise to be leaders in the healthcare transformation conversation to advocate for and play a major role in the years ahead because changes will affect the way patients and their families are cared for. Legislative restrictions, often supported by medical associations' political influence, have produced practice barriers for nurses even when the restrictions lack supporting data.[38] Numerous studies have been published about care provided by APRNs compared to physicians, and they conclude that patient outcomes are similar in terms of safety, effectiveness, quality, and patient satisfaction scores. In some studies, patient outcomes are better than when care is provided by a physician alone.[39] It is vital that governmental officials and policymakers understand the important role APRNs play in providing this care to the most vulnerable in our society. In 2015, approximately 8,000 primary care physicians entered the workforce, yet it is estimated that, in 2020,


Enrollment and Graduations in Nursing Programs
874 Schools

Qualified Applications Turned Away from Entry-level Baccalaureate Nursing Programs: 2004–2016

Percentage Change in Enrollments in Entry-level Baccalaureate Nursing Programs: 1995–2016

Figure 72.1 Key indicators and trends.
Source: Reference 37.

8,500 primary care physicians will retire, exceeding the number entering practice.[40] This is especially alarming since the US population will continue to grow and age. This presents an opportunity for APRNs to meet the monumental healthcare needs of the nation. Many APRNs have already responded to this need as they work in clinics to monitor and adjust medications to stabilize hypertension and diabetes, practice in rural settings where there are limited services, and deliver and oversee complex care in urban acute care facilities as well as in symptom management clinics. Yet while the needs and opportunities for this care exist, there are still barriers for APRNs to provide this care. For example[40]:

- Not all public or private insurance companies pay for nursing services.
- Schools of nursing provide minimal education and clinical experience in primary care.
- Salaries are generally lower in primary care versus acute care.

The need to remain updated on the complex changes in healthcare and to seek further education are responsibilities and privileges of all palliative care nurses as they "ensure that the healthcare system provides seamless, affordable, quality care that is accessible to all and leads to improved health outcomes."[35]

The Landscape of Healthcare Today: A Call to Action to Improve Education for All Nurses

Nurses, who spend more time with patients than any other discipline, assess and manage patients with increasingly complex needs. There are nearly 3 million employed nurses in the United States, representing the largest sector of the healthcare workforce.[41]

Chronic conditions are present in about half of all US adults (117 million people), with a quarter of this population having two or more chronic health diseases.[42] Of the top 10 causes of death in the United States, seven occur from chronic illnesses, including heart disease, cancer, lower respiratory diseases, stroke, diabetes, and kidney diseases.[43] Chronic illness is a personal and social burden and creates a deep economic impact, with 86% ($2.3 trillion) of the $2.7 trillion in annual US healthcare costs spent on the many challenges associated with these diseases.[44] In spite of the prevalence and scope of the problem, very little attention is given to maximizing health potential and improving quality of life (QOL) for those with chronic illness. The number of people in the 65-years-and-older category is expected to double by 2060, representing an increase from 15% to 24% of the overall population.[45]

A ground-breaking report released in 2010 and published by the Institute of Medicine (IOM), *The Future of Nursing: Leading Change, Advancing Health,* highlighted key areas for nursing transformation in an effort to meet these tremendous needs.[35] The result of a 2-year initiative by the RWJF Campaign for Action outlined four key messages that significantly affect the future of nursing[35]:

- Nurses should practice to the full extent of their education and training.
- Nurses should achieve higher levels of education and training through an improved education system that promotes seamless academic progression.
- Nurses should be full partners with physicians and other healthcare professionals in redesigning healthcare in the United States.
- Effective workforce planning and policymaking require better data collection and information infrastructure.

Two of these four key messages specifically address education as it is vital in meeting the complex needs of patients and transforming healthcare systems. In order to provide safe, "seamless, affordable, and quality care," nurses must obtain higher levels of education.[35] Contrary to this initiative, the current US healthcare system and nursing curricula focus on assessing and managing acute illnesses. A drastic change in curricula must take place in order to meet the needs of older adults, many of whom live at home and are seen by nurses in the community who assess and manage complex, chronic comorbidities, including obesity, heart disease, hypertension, and mental illness. Schools of nursing must develop and promote "leadership, health policy, system improvement, research and evidence-based practice, and teamwork and collaboration" competencies in order to provide quality care beyond acute care settings and inclusive of the community, public health, and geriatric settings.[35]

In 2015, the IOM requested an assessment of progress toward implementing *The Future of Nursing* report recommendations. The 2015 report found that significant strides had been made in educating more nurses at all levels of practice, but it also called out the need to develop and evaluate the transition-to-practice programs and the effect of such programs on patient outcomes.[46] In addition, the report recommended incentives for and expansion of programs to promote both DNP- and PhD-prepared nurses, as well as life-long learning. Finally, the report emphasized the need for interprofessional education (IPE) and professional collaboration.

A panel of experts conducted a review of palliative care nursing within the current healthcare systems and identified strategies for nurses to lead in transforming palliative care. Resulting recommendations jointly issued by the ANA and HPNA in the "Call to Action" are aimed at ensuring that "seriously ill and injured patients, families, and communities receive quality palliative care in all care settings. This is achieved by the delivery of primary palliative nursing by every nurse, regardless of setting."[23] Education-focused recommendations suggest that primary palliative care education for undergraduate (baccalaureate), graduate, and doctoral degrees, and continuing education for practicing nurses and advanced practice registered nurses, be based on the ELNEC curricula.[22] The number of employed nurses with baccalaureate degrees continues to grow and is in line to achieve the goal of 80% by 2020.[47]

Primary palliative care is distinguished from specialty palliative care in that primary palliative care contains the core, fundamental skills needed by all clinicians. Included in the *primary palliative care* scope is basic assessment and management of pain and symptoms and improving communication skills related to advance care planning and setting goals of care.[48] *Specialty palliative care* refers to providers equipped with advanced education and certification in this care, addressing more complex and refractory symptoms, possessing advanced communication and conflict-resolution skills, and providing care across settings.[49,50]

In addition to primary palliative care education, nurses are needed in advanced practice roles. The demand for doctoral nursing education is growing rapidly in the United States. Much of this is due to the increase of evidence-based practice, the complexity of patient care due to technology and multiple comorbidities, concerns about quality of care and safety issues, and a shortage of nursing faculty with a doctoral degree, and as a response to healthcare reform. There is evidence of steady increases in employed nurses with doctoral education.[51] The IOM recommendation of doubling the number of doctoral-prepared nurses by 2020 has already been achieved. For example, the number of research-focused doctoral graduates increased by 24.9% between 2012 and 2016, and graduations also increased for DNPs by 161.3% from 2012 to 2016.[51]

Nurses are leaders in providing care across the spectrum of health and illness, and they have an impact on quality, access, and delivery of affordable care. As the population ages and care grows in complexity, palliative care continues to gain momentum in the narrative of care. Nurses will continue to be well-educated and positioned to participate and lead in these changes and to promote policies that outline excellent palliative care. Educators must be poised to meet this challenge.

Interprofessional Palliative Care Education

IPE is a strategy embraced in both education and practice. Palliative care is by nature an interprofessional specialty and a well-established exemplar of team-based care. IPE is a logical platform for engaging students in discipline-specific and cross-discipline knowledge, skills, and competencies, thus fostering greater appreciation and attitudes toward the unique and synergistic contributions each profession brings to palliative care as well as posing opportunities to break down barriers. The IPE narrative began in the early 1970s by encouraging academic centers to provide team-based experiences. Head and colleagues summarized the discourse and magnitude of the imperative, which gained traction in 2010 with reports from IOM and a World Health Organization report.[52] Recent efforts have proved promising in the use and impact of palliative interprofessional training on the attitudes, knowledge, and behavior of nursing and medical students in caring for those with serious illness, although standards for such training do not yet exist.[53–55]

The new competencies (CARES) document for undergraduate nursing education twice references IPE as it relates to collaboration and communication toward quality, patient-centered outcomes in palliative care.[5] The increase in palliative and EOL education in prelicensure nursing programs, medical school curricula, and specialty journals and textbooks is promising. However, most healthcare provider programs still lack formal curricular integration of these concepts.[29,52] It will take normalizing of care and communication within the training milieu before the paradigm in practice can shift. Key leaders in palliative medicine and nursing have developed core competencies for their respective disciplines in training medical and nursing students to care for seriously ill patients and their families, but widespread integration into curriculum is still lacking.[5,56,59] As von Gunten and Ferrell (2014) remind us, "the greatest mistake in medical and nursing education and training is to view it as a cognitive exercise."[58(p. 226)] There is an imperative for academia to provide evidence-based knowledge and role-model the skill and practice of palliative care.[5,38,61]

Higher education and certificate programs are beginning to emerge, and, as stated by the ANA, nurses are "leaders in developing, promoting, implementing, and sustaining such teamwork in palliative care."[6(p. 8)] Exemplars of such initiatives are summarized in Table 72.3.

Promoting Palliative Education, Certification, and Scholarships

The 2013 National Consensus Project's (NCP) *Clinical Practice Guidelines for Quality Palliative Care* has been a roadmap used by numerous nursing educators, clinicians, and researchers to develop palliative care programs and curricula, research studies, protocols, and annual competencies.[9] Now, in its fourth edition, the guidelines expand ways to "improve access to quality palliative

Table 72.3 Examples of interprofessional education and certificate programs in palliative care

Program	Interprofessional disciplines
Academic	
Yale School of Medicine Palliative and End of Life Education: http://palliativecare.yale.edu/education/index.aspx	Medicine, nursing, divinity school, social work
University of Louisville Schools of Nursing and Medicine Interdisciplinary Curriculum for Oncology Palliative Care Education (iCOPE): http://uoflnews.com/post/uofltoday/uofl-developing-program-to-guide-other-universities-in-teaching-palliative-care/	Students of social work, nursing, medicine, and chaplaincy
University of Colorado Denver—Graduate School Interprofessional Master of Science in Palliative Care and Palliative Care Certificate Programs: http://www.ucdenver.edu/academics/colleges/Graduate-School/academic-programs/Palliative%20Care/Pages/default.aspx	Students of nursing, medicine, pharmacy, practicing physician assistants, pharmacists, social workers, spiritual care providers, psychologists, therapists, counselors, ethicists
Certificate Programs	
University of California San Francisco School of Nursing Interprofessional Continuing Education in Palliative Care: https://nursing.ucsf.edu/palliative-care/continuing-education	Nurses, advance practice nurses, physicians, chaplains, community-based clergy, social workers, pharmacists, nursing aides, case managers, psychologists, therapists, family support coordinators, interpreters
University of Washington Interprofessional Graduate Certificate in Palliative Care: http://depts.washington.edu/pallcntr/palliative-care-training-center.html	Clinicians providing primary or specialty palliative care; integrates Interprofessional team training
Grand Valley State University Interprofessional Certificate Palliative and Hospice Care http://www.gvsu.edu/phc/	Any discipline with a bachelor's degree may apply

care for all people with serious illness, regardless of setting, diagnosis, prognosis, or age."[59]

Because of these guidelines and their direction in practice, nurses have a clearer understanding of the importance of becoming better educated and even seeking certification in palliative nursing. Belonging to an organization where nurses can meet and learn from each other is critical to professional growth. The HPNA provides educational resources and opportunities, position statements, conferences, and support to APRNs, registered nurses, licensed practical/vocational nurses, nursing assistants, and administrators.[60] There are approximately 11,500 HPNA members in the United States and in several foreign countries.[61] HPNA provides educational opportunities through continuing education via webinars, ELNEC train-the-trainer courses, special interest groups (SIGs), online chats, and publishing resource books. In addition, meetings such as the Leadership Week-End Conference, Clinical Practice Forum, and the Annual Assembly, co-sponsored by HPNA and the American Academy of Hospice and Palliative Medicine (AAHPM), provide opportunities to network with other nurses and members of the interprofessional team. Hospice and palliative nurses can stay updated on the latest evidence-based practice through articles found in the *Journal of Hospice and Palliative Nursing* (JHPN) and through an online subscription to the *Journal of Palliative Medicine* (JPM). For more information regarding HPNA, go to www.advancingexpertcare.org.

One of two affiliated organizations within HPNA is the Hospice and Palliative Credentialing Center (HPCC), http://hpcc.advancingexpertcare.org/, the only organization that provides specialty certification for all levels of hospice and palliative nursing. There are currently seven certification exams offered by HPCC: Advanced Certified Hospice and Palliative Nurse (ACHPN), Certified Hospice and Palliative Nurse (CHPN), Certified Hospice and Palliative Pediatric Nurse (CHPPN), Certified Hospice and Palliative Licensed Nurse (CHPLN), Certified Hospice and Palliative Nursing Assistant (CHPNA), Certified Hospice and Palliative Care Administrator (CHPCA), and Certified in Perinatal Loss Care (CPLC). Currently, there are 18,809 certificants across all seven certifications (personal communication from S. L. Shafer, July 28, 2017).

The second organization affiliated with HPNA is the Hospice and Palliative Nurses Foundation (HPNF), incorporated in 1998, and it is committed to raising awareness and funding ways to support professional development of hospice and palliative nurses. As a 501(c)(3), the Foundation provided nine scholarships for education, research, conferences, and certification in 2016.[60] For further information on HPNF, go to http://hpnf.advancingexpertcare.org/.

International Efforts to Educate Nurses in Palliative Care

Each year, 40 million seriously ill children and adults around the world could benefit from palliative care, yet it is estimated that one-third of the world has no access to palliative care.[61,62] This is unfortunate because the world's aging population and cancer rates are increasing not only in the United States and other developed countries, but also in resource-poor countries. Nurses around the globe are responding to the tremendous needs to care for people who are suffering and dying, and they are becoming educated so they can provide evidence-based care. Yet there are barriers to providing palliative care education throughout the world[62,63]:

- Unawareness of and/or confusion about palliative care services.
- Poor or nonexistent support and advocacy on behalf of governments, ministries of health, and nongovernmental organizations (NGOs).
- Lack of access to opioids.
- Lack of education for healthcare professionals.

While there are tremendous needs and barriers, education is vital in responding to them. Today, there are variations in the establishment of palliative care educational programs around the world. For example, there are both stand-alone palliative care courses and courses where palliative care concepts are woven into already existing curricula in universities, seminars, workshops, and conferences in the Americas, Africa, Asia, Australia, the United Kingdom, and northern/eastern Europe, as well as in the Middle East.

Since 2004, there has been a widespread effort to expand ELNEC internationally.[28] Today, ELNEC has been presented in 96 countries, representing six of the seven continents. The ELNEC-Core curriculum has been translated into nine languages: Albanian, Chinese, Czech, German, Japanese, Korean, Romanian, Russian, and Spanish. Nursing leaders throughout these nations have led the way to make sure healthcare professionals have a thorough and up-to-date curriculum. In addition, ELNEC faculty from the United States has dedicated time to develop and deliver leadership seminars to palliative care visionaries throughout Eastern Europe, Kenya, and Asia. Efforts by several international nursing leaders in disseminating ELNEC through various educational means include[66–68]:

- Nicoleta Mitrea, PhD, APRN, MSc, is a lecturer at the Transylvania University Medical School and an APRN and researcher at the Casa Sperantei, Brasov, Romania.
- Juli Boit, MSN, RN, FNP, is the director of Living Room International and founder of Kimbilio, a 24-bed hospice and palliative care inpatient facility in Kip Karen, a rural community in Kenya.
- Joan "Jody" Ramer Chrastek, DNP, CHPN, is the pediatric advanced complex care team coordinator at the Fairview Home Care and Hospice in Minneapolis, Minnesota, and has spent many years volunteering in India to educate, translate ELNEC into Hindi, and empower nurses in palliative care.
- Sayaka Takenouchi, PhD, RN, MPH, is a senior lecturer at the Department of Ethics Support, Kyoto University Hospital, Kyoto, Japan, and, with her team, has translated ELNEC-Core, ELNEC-Geriatric, ELNEC-Critical Care, and ELNEC-Pediatric Palliative Care into Japanese.
- Hyun Sook Kim, PhD, RN, MSN, MSW, is a Professor in the Department of Nursing, Korea National University of Transportation, Jeungpyeong, Chungbuk, South Korea, and she has led the efforts to translate ELNEC-Core, ELNEC-Geriatric, ELNEC-Pediatric Palliative Care, and ELNEC-Critical Care into Korean.

For more information about ELNEC-International, go to http://www.aacnnursing.org/ELNEC/International.

Conclusion

As stated at the beginning of this chapter, there has never been a more exciting time to teach palliative care. It is rewarding to report the progress that has been made over the past 20 years in palliative care nursing, both within schools of nursing as well as across settings for practicing nurses. The science of palliative care as well as the shift in national directives and resources has contributed greatly to this progress. The literature has reported that nurses feel inadequately prepared in palliative care, and nursing faculty are on the cusp of shifting this paradigm.

Not only do patient outcomes, quality of care, and costs of care improve with palliative care, so do future practicing nurses and physicians. Many studies have reinforced the benefits of in-program training and education to their knowledge, sense of confidence, level of anxiety, and comfort in caring for those with serious illness and the dying.[53,54,69,70] Educators must foster excellence in palliative care practices through education, skills-building, and practice opportunities.

Now that palliative care has expanded from EOL care to address the QOL and symptom management needs of patients living with serious illness/injury and has demonstrated both patient satisfaction and cost-effectiveness, palliative care is being adopted rapidly in both inpatient and outpatient settings. As a result, employers are expressing the need for educated palliative care professionals. Unfortunately, there are not enough educated personnel to meet the workforce demand, and thus challenges remain.[71] Nurses must take opportunities to acknowledge and understand these challenges and work collectively to overcome them.

Teaching palliative care is not purely a cognitive exercise. Academia and professional training must provide evidence-based knowledge and role-modeling of the skill and practice of palliative care. Students and practicing nurses need to envision what excellent palliative care can look like.

Teaching and guiding students requires compassion and exquisite attention to respecting students' and practicing nurses' values, beliefs, personal experiences, and culture. It is essential that palliative care education not only incorporate knowledge and skills but also strive to teach effective ways of knowing how to best enhance compassion for those who suffer, empathy for those without a voice, and the "art" as well as the science of palliative nursing to patients and families who desperately need this care. It is a privilege to provide this education!

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CHAPTER 73

Nursing Research

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Key Points

- The goal of nursing research is to improve care for patients and their families.
- Nurses have been instrumental in the field of palliative care research and are in ideal roles to be involved in or lead palliative care research.
- Palliative nursing research includes many sensitive topics such as suffering, quality of life, communication about death, and life meaning.
- Nurse researchers face many obstacles in conducting research, such as obtaining informed consent, dealing with vulnerable populations, and openly discussing end-of-life issues with patients and families.
- Palliative nursing research should utilize an interdisciplinary model that includes all supportive care disciplines.

Introduction

The ultimate goal of nursing research, and indeed of nursing knowledge, is to improve patient care. Palliative care science develops strategies to decrease suffering and enhance life for individuals living with, suffering from, and dying of life-threatening conditions and their family members. Palliative care research includes physical, emotional, social, and spiritual domains and informed decision-making support.[1] Nurses are in ideal roles not only to be part of palliative care research, but also to serve as leaders in the field to advance the science of palliative care.

Nurses led some of the earliest palliative care research contributions.[2] Pioneering work by Benoliel and others raised awareness of deficiencies in the care of the dying.[3,4] Early descriptive studies documented the influence of nursing attitudes and beliefs about death on the care provided to patients. From the earliest studies in the 1960s to the "awakening" of attention to palliative care in the late 1990s, research in palliative care has been limited. Nurse investigators have addressed aspects of palliative care such as symptom management, bereavement, communication, and care of special populations such as dying children.

Historically, there has been a lack of support for palliative care nursing research. National initiatives are increasingly supportive of palliative care research. For example, the National Institute of Nursing Research (NINR) has been designated as the lead institute at the National Institutes of Health (NIH) in the area of end-of-life and palliative care.[5] The Office of End-of-Life and Palliative Care Research coordinates NINR and NIH palliative care research efforts including (a) stimulating research opportunities in palliative care, (b) creating opportunities for collaboration, (c) facilitating interdisciplinary palliative care research, and (d) identifying opportunities for palliative care research to inform practice and policy. The Palliative Care Research Cooperative was established in 2010 to develop scientifically based methods that lead to meaningful palliative care evidence by creating a community of palliative care investigators, including nurses, who can engage in research discovery.[6] While such palliative care initiatives at the national level have improved support and funding for palliative care research, stronger support specific to nursing science in palliative care is needed. Nurses are in ideal roles to step up as leaders to further advance the field of palliative care nursing science.

Goals of Palliative Care Research

Goals of nursing research in palliative care ultimately focus on capturing evidence to improve the outcomes of patients with life-threatening or life-limiting conditions. Palliative care nursing research focuses on discovery, quantification, descriptions of phenomena, quality improvement, and problem-solving.[7]

Defining palliative care and understanding its ramifications have received increased attention but remain relatively unexplored areas, resulting in many opportunities for discovery. For example, more studies need to focus on the unique role of nursing within an interdisciplinary team and the greatest needs of patients receiving palliative care and their caregivers. Descriptive studies and epidemiological approaches can assist in quantifying advanced disease symptoms, including severity and impact. The experience of dying coupled with the subjectivity implicit in pain and terminal illness call for research methods that describe phenomena in context. Studies have identified gaps in palliative care such as end-of-life (EOL) care.[8,9] Research is needed to fill such gaps and improve the quality of care at the end of the illness trajectory.

While knowledge about the care of families receiving palliative care is expanding, current goals focus on defining populations of interest in addition to oncology patients, developing methods to measure various phenomena, and learning more about the development of patient and family indicators.[10] Oncology was understandably the discipline that received the most attention in early research in palliative care because funding was generally available and success rates of cure were relatively low. Research going forward could benefit from a focus on other populations such as those with heart conditions, autoimmune disorders, respiratory diseases, neurological conditions, and trauma.

Recent health policy changes such as the Affordable Care Act have resulted in innovative models of care. Research is needed to examine fixed components of care compared with aspects amenable to modification to achieve improved outcomes. Specifically, it is incumbent on researchers to study the infrastructure needed to maintain new models of care.

The Hospice and Palliative Care Nurses Association (HPNA), a national palliative care organization for nurse clinicians, researchers, and academics, conducted a member survey to identify goals of palliative care research. Results focused on palliative and EOL care for patients of all ages experiencing a life-threatening or life-limiting condition and included structure and processes of care, physical aspects of care, and psychological aspects of care.[7] Although the field of palliative care is developing through research, more work is needed to address the goals of professional palliative care organizations such as HPNA and the needs of this vulnerable patient population through discovery, quality improvement, and symptom management.

Benefits and Challenges in Palliative Care Research

Research in palliative care includes unique benefits and challenges. Considerable agreement about research priorities over the past 15 years is evident through systematic reviews and conference proceedings. Although a widely endorsed research agenda exists, the state of the science has progressed relatively slowly, suggesting the presence of considerable challenges in the field.[11] While even a mention of conducting research with patients who have received a life-threatening or life-limiting diagnosis raises concerns related to their vulnerability, there are also benefits to participants in research during this difficult journey.

Even when patients feel most vulnerable, having an opportunity to help others through enhancing healthcare providers' awareness and understanding of best practices, symptom management, and access to care is often very rewarding. Participating in research may offer an opportunity to derive some meaning from their experiences and to feel their suffering may even benefit others.[12] Participants may derive therapeutic benefits from telling their stories. In studies involving interviews with bereaved parents and siblings, parents frequently offered positive feedback and thanks to researchers for caring enough to listen to their stories and working toward improving the care of families after the death of a loved one.[13]

In contrast, challenges and barriers in palliative care research are widespread. The multidimensional interdisciplinary aspects of palliative care and the vulnerability of the population are two examples that pose special challenges to this area of research. Challenging areas include ethical concerns, financial/time constraints, research design questions, human resource limitations, and institutional politics (Figure 73.1).[14]

Staying true to the ethical principles of beneficence and nonmaleficence, as clinicians, nurses strive to enhance a patient's

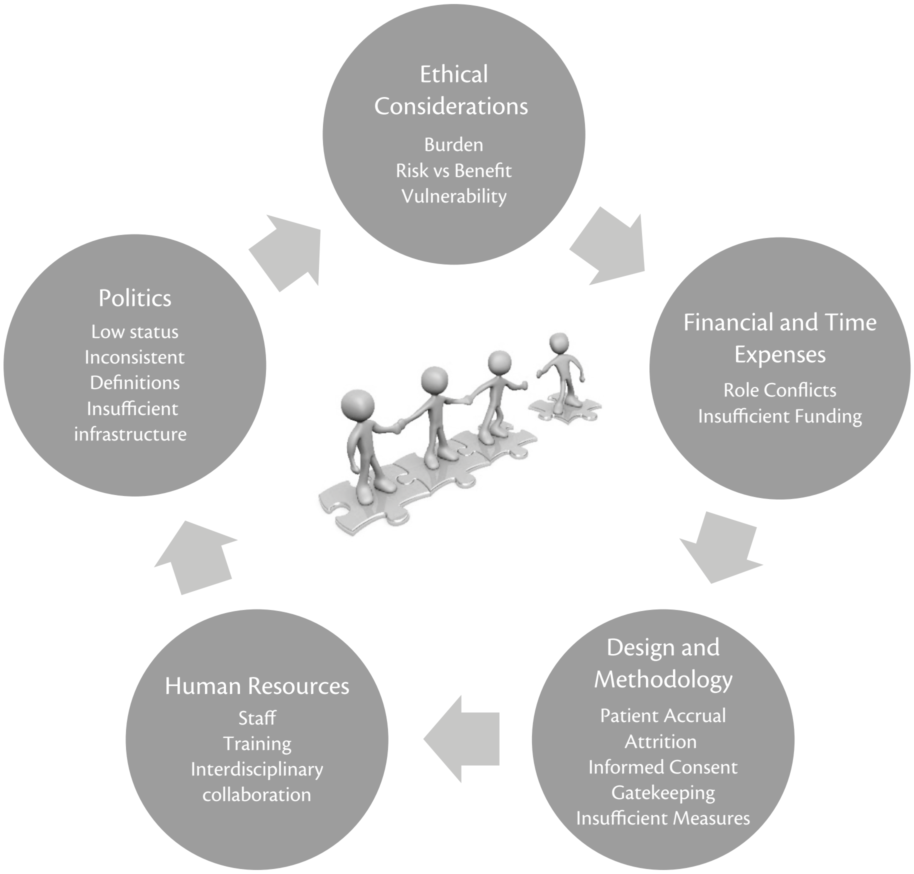
Ethical Considerations
Burden
Risk vs Benefit
Vulnerability
Financial and Time Expenses
Role Conflicts
Insufficient Funding
Design and Methodology
Patient Accrual
Attrition
Informed Consent
Gatekeeping
Insufficient Measures
Human Resources
Staff
Training
Interdisciplinary collaboration
Politics
Low status
Inconsistent Definitions
Insufficient infrastructure

Figure 73.1 Challenges and barriers to palliative care research.

well-being and quality of life (QOL) while, as researchers, they must be careful not to confound data. Another ethical principle, autonomy, plays into the challenges of gaining informed consent from debilitated and declining patients as nurses strive to protect patient and family independence. Potential research participants may feel obligated to agree to engage in the research, particularly when they are the recipients of high-quality care and feel indebted to providers. While all patients receiving palliative care are vulnerable, some groups, such as children, those with cognitive impairment, the poor, and the elderly, are particularly at risk.[13,14]

Funding and time limitations are often barriers to palliative care research. Telephone interviews with 61 leading researchers in palliative care identified funding and institutional capacity as barriers that limit progress in the field of palliative care.[11] Respondents described a limited number of funding sources and the review process of proposals as blocks to funding. Although community-based palliative care is growing, few outpatient palliative care services exist or have the capacity to conduct research. Palliative care services often are integrated into departments of geriatrics or oncology and may have few dedicated resources for internal research activities. Nurses often serve in roles of recruiters or data collectors for studies. A nurse may have difficulty balancing the role of a researcher with the role of a clinician, wanting to mitigate symptoms rather than assess them.

Design concerns may manifest through Institutional Review Board (IRB) proposals, informed consent of compromised patients, unwillingness to talk about the dying process, attrition, the emotions of both research staff and families, and a lack of appropriate measures. Hospital IRBs may be hesitant to approve protocols that involve families from the time of a difficult diagnosis through the illness trajectory that proceeds to end of life. Subject burden must be taken into consideration in palliative care, perhaps more than in any other field of study. As mentioned earlier in discussing the benefits of palliative care research, however, participants may welcome an avenue for communicating their needs and their successes. Potential attrition needs to be considered in determining sample sizes and becomes a real concern when longitudinal studies are proposed, which are definitely needed in palliative care research. Both qualitative[15] and quantitative[16] approaches are useful in the emerging science of palliative care.

Definitions of palliative care are disparate and may not be understood by the general population, leading to misunderstandings and potential conflicts. Another challenge is that palliative care is not generally revenue-producing, and its status may not measure up to specialties such as cardiovascular surgery. A research team with members who are passionate about palliative care, knowledgeable, caring, and insightful must be recruited to conduct the research, and burnout remains a constant threat. Interdisciplinary collaboration is a key to success with these complex patients. Finally, life-threatening conditions are shared experiences, and including families in the research enriches the benefits of palliative care research.[9,17]

Priority Research Areas in Palliative Care

In the past twenty years, palliative care research has focused on efforts to fill the gaps in knowledge identified by multiple initiatives. Palliative research has historically focused on symptom management, health systems, cultural considerations in care, QOL of patients and their caregivers, needs of caregivers, and emotional and spiritual aspects of living with a terminal illness.[18] Although these topics are relevant and important in palliative care research, it is imperative that gaps continue to be identified to address ever-changing healthcare delivery systems, care models, costs of care, and needs of patients and caregivers.

In 1997, the NIH appointed the NINR as the lead institute of end-of-life and palliative care research. With the support of the NIH, the NINR released a report of trends in scientific literature focusing on palliative care between 1997 and 2010. The results of the extensive review showed that although there was significant growth in end-of-life and palliative care nursing research during this time period, knowledge gaps remained and these persist today. The gaps were identified in the topic areas of changing demographics of patients with serious illness and EOL palliative care issues related to renal or liver disease, as well as HIV/AIDS and pediatric populations. In addition, there was a lack of literature pertaining to ethnic, cultural, and spiritual needs (Box 73.1).[19] In 2011, the NINR led The Science of Compassion: Future Directions in End of Life and Palliative Care Research Summit to assess the gaps in knowledge in end-of-life and palliative care and to further the agenda for future research. Some of the proposed future agenda items were ethical aspects of palliative care, early versus delayed access to care across disease processes, integrated models of care, improved communication, more community involvement, and a need for more longitudinal studies.[20,21]

Also during this time of tremendous growth in palliative care research, the HPNA[7] presented a 2015–2018 research agenda consisting of topics to provide direction for research: (1) provide focus for graduate students and researchers, (2) guide organizational and research funding, and (3) illustrate to other stakeholders the importance of specific research foci. As a framework for these agenda items, the *Clinical Practice Guidelines for Quality Palliative Care* released by the National Consensus Project for Quality Care provided eight domains essential to providing high-quality palliative care that are considered to be the highest priority for current and future nursing research. These domains are structures and processes of care; physical aspects of care; psychological and psychiatric aspects of care; social aspects of care; spiritual, religious, and existential aspects of care; cultural aspects of care; care of the patient at end of life; and ethical and legal aspects of care.[7]

In addition, the Institute of Medicine's (IOM) report has highlighted areas for improvement in providing quality palliative care for patients and their caregivers.[15] The report contained five recommended areas for improvement in care: delivery of care, clinician–patient communication and advance care planning, professional education and development, policies and payment

Box 73.1 NIH/NINR Identified Gaps in Nursing Research

End-of-life palliative care (EOL PC) issues related to:

1. The changing demographics of patients with serious illness
2. Renal or liver disease end-of-life palliative care issues related to HIV/AIDS
3. Pediatric populations
4. Ethnic needs
5. Cultural needs
6. Spiritual needs

Box 73.2 IOM: Recommended Areas for Research/Improvement in End-of-Life Care

1. Delivery of care
2. Clinician–patient communication and advance care planning
3. Professional education and development
4. Policies and payment systems
5. Public education and engagement

systems, and public education and engagement that can be used to help guide future nursing research in palliative care (Box 73.2).[22]

The continued interest in palliative nursing research is evidence that there is room for discovery in what nurse scientists know about palliative care and room for improvement in how the information is translated into best practice. The research focus areas suggested by the NIH/NINR, HPNA, and IOM are those areas with significant gaps in palliative care literature to date and should be used to guide future research directions. Nurse scientists and clinicians must collaborate to identify best strategies to translate findings into practice in a meaningful way if palliative care practice is to evolve and improve based on emerging research.

Palliative Care Funding Sources

Numerous organizations support palliative care and provide funding opportunities for research. Palliative care funding is available for many investigative levels, including predoctoral students, postdoctoral fellows, junior faculty researchers, and senior scientists. Researchers should consider potential internal hospital and institutional funding mechanisms in addition to external funding mechanisms such as private organizations, industry, and the NIH. Examples of funding sources that can support palliative care research are listed here.

- American Cancer Society: https://www.cancer.org/research/we-fund-cancer-research/apply-research-grant.html
- American Nursing Foundation: http://www.anfonline.org/nursingresearchgrant
- Hospice and Palliative Nursing Association: http://advancingexpertcare.org/research-grants/
- National Institute of Nursing Research: https://www.ninr.nih.gov/researchandfunding/dea/desp/oep/fundingopportunities
- National Palliative Care Research Center: http://www.npcrc.org/content/19/Funding-Opportunities.aspx
- Palliative Care Research Cooperative: http://palliativecareresearch.org/funding/funding-opportunities/

Table 73.1 Research proposal components

Specific aims	Clearly stated. Hypotheses or study questions are consistent with the study aims. All proposed study procedures and data to be collected are encompassed. Guided by a clear theoretical/conceptual framework
Significance	Research has high impact and advances the science of palliative nursing care. Research has strong potential to lead to further investigation. Research offers a unique contribution to the literature. Research is clinically relevant to palliative care. Relevant and current literature is reviewed, critiqued, synthesized, and analyzed.
Innovation	Is pioneering in the field of palliative care Seeks to shift palliative care paradigms Develops new theories, tools, approaches Accelerates or strengthens existing palliative care research or practice
Approach	Procedures are feasible. Procedures include methods for training and supervision of personnel. Procedures provide sufficient description of precisely what will be required of subjects. Statistical procedures are identified, and analysis is appropriate for the type of data and study design and answers the study questions. Well-designed tables and figures. Feasible study timeline, typically in table format.
Human subjects	Institutional Review Board approval is given or documentation of pending review is given. Investigator is clearly aware of the impact of participation in the study on the subject. Investigator addresses concerns regarding length, intrusiveness, and energy expenditure required. Investigator has acknowledged special considerations of patients with life-threatening conditions.
Investigators	Consultation is available for the less experienced researcher. Role of co-investigators or consultants is established.
Format	The proposal strictly adheres to format restrictions and page limitations.

Table 73.2 Tips for preparing research proposal

Team effort	Seek consultation and collaboration from others, especially senior palliative care researchers. Seek opportunities to involve interdisciplinary clinical palliative care team members (e.g., nurse practitioners, physicians, social workers, psychologists, child life specialists) in nursing research.
Peer review	Have peers review proposal before submission. A proposal submitted for funding is generally the product of numerous revisions.
Follow directions	Follow the directions in detail, including margins, page limits, and the use of references and appendices. Communicate directly with the funding source to clarify any directions.
Writing	State clear and concise ideas. Word economy is essential to a fine-tuned proposal.
Proofread	Proofread carefully. Do not allow grammatical errors or typos. Grant reviewers want to see that you have given attention to detail in the preparation of your proposal.
Time frame	Plan ahead and develop a time frame for completing your grant. Grant proposals cannot be written at the last minute. Strictly adhere to all deadlines, including internal deadlines within your organization.
Appendices	Use appendices to include study instruments, procedures, or other supporting materials *if allowed*.
Support letters	Include support letters from individuals who are important to the success of your study. This includes department chairs, medical staff, nursing administration, consultants, and co-investigators.
Start small	Successful completion of a pilot project is the best foundation for a larger study. Efficient use of small grant funding is influential when seeking larger scale funding for major proposals.
Be realistic	Design research projects that can be realistically accomplished within the scope of your other responsibilities and the limitations of your work setting.
Patient focus	Design and implement research that is relevant to patient care and improves quality of life and decreases suffering for patients with life-threatening conditions and their families.

- Sigma Theta Tau: https://www.sigmanursing.org/advance-elevate/research/research-grants

Preparation of a Research Proposal

Components of a research proposal are specific to the funding mechanism, yet content is similar in the majority of proposals. Table 73.1 includes an example of guidelines for preparing a research proposal. These criteria, adapted from the NINR,[23] depict the essential elements of a research proposal: specific aims, significance, innovation, approach, human subjects, investigators, and format. Table 73.2 includes general tips for preparing a research proposal. Attention to the criteria that reviewers will use to assess and score the application can also help in preparing the proposal. Review criteria differ according to funding mechanism and organization. NIH review considerations are summarized in Table 73.3.

Conclusion

Research is essential to advance the science of palliative care to inform practice. Leading organizations highlight research agendas to help identify important areas in need of study in palliative care. Numerous opportunities are available to fund rigorous studies that will significantly impact the field of palliative care and ultimately improve patient care. The palliative care research community is interdisciplinary and collaborative in nature. We should continue

Table 73.3 Review considerations for research sponsored by the National Institutes of Health (NIH)

Significance	Does this study address an important problem? If the aims of the application are achieved, how will scientific knowledge be improved? Is there a strong scientific premise?
Investigator	Is the investigator appropriately trained and well suited to the project? Is the work proposed appropriate to the experience level of the principal investigator and other researchers (if any)?
Innovation	Does the project shift research or practice paradigms forward? Does the study use novel concepts, approaches, or methods? Are the aims original and innovative? Does the project challenge existing paradigms? Does the study develop new theory, methodologies, instruments, or interventions?
Approach	Are the conceptual framework, design, methods, and analyses adequately developed, well integrated, and appropriate to the aims of the project? Are potential problems and possible solutions addressed? Does scientific rigor ensure robust and unbiased study results? Are relevant biological variables (e.g., sex, age, weight, underlying health conditions) addressed?
Environment	Does the scientific environment in which the work will be done contribute to the probability of success? Is there evidence of institutional support? Does the project benefit from unique features of the research environment, study populations, or collaborations?
Additional considerations	Adequacy of plans to include both genders and minorities and their subgroups as appropriate for the scientific goals of the research are reviewed. Plans for the recruitment and retention of subjects are also evaluated. Rigor and reproducibility should be addressed.

Source: From References 24 and 25.

efforts to support and develop the next generation of nurses to become leading independent palliative care researchers. Nurses are vital to advancing the science of palliative care research and are in ideal roles to not only support, but also to lead innovative palliative care research that will enhance life and decrease suffering for the patients and families that we serve.

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CHAPTER 74

Advocacy in Palliative Nursing

A Conceptual Model

Nessa Coyle and Timothy W. Kirk

Key Points

- Nurses are ideally suited to advocate for patients and families due to their professional orientation, education, and role in patient care.
- Six components constitute a model of advocacy in palliative nursing: clinical competency, relational care, communication skills, bio-psycho-social-spiritual orientation, interdisciplinary collaboration, and a combination of confidence and humility.
- Nurse advocates respond to the strengths as well as the vulnerabilities of patients and families, building empowering relationships to support care decisions that respect the values and personhood of patients.
- Seven functional elements facilitate effective advocacy in palliative nursing: specific documentation, careful observation of patient and family interactions, assessing understanding, building rapport, eliciting care preferences, privileging patient values and preferences, teaching and sharing information.
- Advocacy is an *approach* to palliative nursing care, one which emphasizes careful attention to process over outcome.

Case Study: Advocating for a Patient—Part 1

Mr. O'Reilly is a 75-year-old retired literature professor, married with three adult children—two daughters and one son. One daughter was a writer and a stay-at-home mom; the other worked in a law firm. Both have young children. The son was in graduate school studying business management and communication. The children and their families lived nearby, and this basic family structure appeared to be a close-knit one. Mr. O'Reilly and his wife were originally from Ireland. They moved to the United States to attend university, became citizens, and have lived in the country for more than three decades. Their three children were born and educated in the United States. Mr. O'Reilly described his family as being the most important aspect of his life.

Mr. O'Reilly was diagnosed with incurable lung cancer 5 years ago, and the disease was initially controlled with multiple chemotherapy regimens. He now had end-stage disease, including newly diagnosed metastases to the brain, leptomeninges, and skeletal system. Over the past year, he had become increasingly dependent on his family for his basic needs.

His last chemotherapy treatment was 8 months ago. At the time of that visit and following a frank and open discussion with his oncologist, Mr. O'Reilly declared his preference for a do not attempt resuscitation (DNAR) code status and to allow a natural death (AND) when "my time comes." There was no note in the chart as to whether a family member was present during the code status discussion or if it was discussed with the family at a later date. At his request, Mr. O'Reilly was referred to the Integrative Medicine Service, and turned the focus of his care toward nutrition, exercise, and meditation. He was also referred to the outpatient palliative care clinic for support and ongoing management of pain and dyspnea.

Several months later, Mr. O'Reilly's final hospital admission was through the emergency department for increasing shortness of breath and hypoxia. On admission, he looked frail, cachectic, and close to death. He complained of generalized pain. Consistent with his previously stated wishes, and following a conversation with his attending physician in the emergency department, his code status was established as DNAR and AND. On the inpatient floor, his analgesic regimen was adjusted, and he was placed on high-flow nasal oxygen. His symptoms were brought under control, and he was able to communicate clearly.

After several days on the unit, Mr. O'Reilly's nurse walked into the room one morning and was handed, by the son, a handwritten note, signed by the patient and all members of his immediate family, stating that he wished to rescind his DNAR order. Goals of care became less clear. Prior to this code status change, when speaking to the nurse alone, Mr. O'Reilly expressed being tired of "the struggle" and just wanting to be kept comfortable. But when his family was present, he expressed the wish to keep fighting for as long as he could; he "had a book to finish." The request to rescind the DNAR order was strongly endorsed by the family. The staff became concerned that Mr. O'Reilly's "true wishes" were being muffled by the strong voice of the family.

Chapter Goals

This chapter addresses four questions related to nursing advocacy:

1. What does it mean for a nurse to "advocate" for a patient like Mr. O'Reilly?
2. In what way(s) is advocacy part of palliative nursing?
3. What kind(s) of communication, and with whom, is necessary for effective advocacy in palliative nursing?
4. How does a palliative care nurse develop/strengthen her skills as a nurse advocate?

The chapter is presented in four parts:

I. Literature review
II. Conceptual model of advocacy in palliative nursing
III. Functional elements of advocacy in palliative nursing
IV. Barriers to anticipate and pitfalls to avoid when advocating in palliative nursing.

A working presumption of the chapter is that *any* nurse working with a patient who has advanced illness has the obligation to provide palliative nursing at a generalist (basic) level.[1] Although it is anticipated that the model of advocacy presented here will also apply to palliative nursing at a specialist level, the chapter is intentionally written with the nonspecialist inpatient nurse in mind.[2,3]

Literature Review

While there is not a peer reviewed literature on advocacy specific to palliative nursing, advocacy is frequently put forward as a core function of ethical nursing practice generally.[4–6] Indeed, some influential nursing theorists have gone so far as to claim that effectively advocating for patients is one of the defining elements of what it means to be a nurse—what makes nursing, "nursing."[7,8] While there may be widespread agreement on the importance of advocacy in nursing, there is considerable heterogeneity on the meaning of advocacy in nursing. A review of several prominent approaches will inform development of our concept of advocacy in palliative care nursing. Readers will note that several of the sources reviewed herein were published prior to 2013. They are included to engage important conceptual work in nursing advocacy and to refer readers to primary sources rather than secondary analyses.

The most prevalent conceptual approach to advocacy in the nursing literature is to position the nurse as a defender of patient rights.[9] This "rights protection" model of advocacy sees the nurse as acting in response to the vulnerability of patients.[6,10] Conditions of patienthood create vulnerability insofar as (a) patients are weakened by illness and injury, (b) there is a significant imbalance in knowledge and experience between patients and the clinicians providing their care, and (c) the structures and practices through which healthcare is delivered are insufficiently designed to elicit patient values and ensure that care is given in alignment with informed patient choices. Actions of the nurse as advocate in this model are interventions to mitigate the threat to patient rights presented by these conditions: (a) carefully assessing patients' symptom distress and collaborating with the care team to optimize symptom management, (b) providing patients the information and understanding necessary to make informed choices, and (c) interceding with the care team on behalf of the patient.

In their mid-range theory of patient advocacy, Bu and Jezewski[11] refine the notion of "rights protection," presenting it as "safeguarding patients' autonomy," which, along with "acting on behalf of patients" and "championing social justice in the provision of healthcare," constitute the three core attributes of patient advocacy. Via a synthetic review of the nursing literature, the authors claim that these three attributes frame a conceptual definition that can be used to develop an operational concept of advocacy.

While a rights protection approach to advocacy is driven by a response to patient vulnerability, an alternate approach emphasizes empowering patients and families by engaging their strengths. Gaylord and Grace,[12] for example, describe advocacy as being embedded in multiple domains of nursing practice, manifesting in each interaction for which a nurse supports a patient to understand and adapt to the meaning of health or illness as uniquely experienced by that patient. Grace[13] further refines this approach to advocacy, one she terms "professional advocacy," by explaining that nursing advocacy attends not only to protecting the rights of patients, but also to creating a care environment in which patients can draw upon their own strengths and partner—with nurses, family members, other care team members—to create and respond to the meaning of their clinical situations in a manner that engages and expresses their personhood.

This alternate approach to advocacy resonates strongly with Gadow's concept of "existential advocacy": "that individuals be *assisted* by nursing to *authentically* exercise their freedom of self-determination."[8(p. 85)] In existential advocacy, nurses build relationships with patients and family members with the aim of empowering them as persons; it is a relational model of supportive partnership wherein the significance of clinical care is always rooted in the ability of that care to enable patients to more fully realize all aspects of who they are as persons. Existential advocacy requires what Kirk[14] calls "clinical intimacy," in which nurses partner with patients using cognitive and behavioral cues to co-create meaning through shared perceptions of the patient's illness and treatment.[15] The aim of such partnering is to offer a supportive presence that empowers patients to create the meaning necessary to (a) cope with the stress that can accompany serious illness and its treatment and (b) make care decisions consistent with their core values and preferred processes of perception and judgment.[16]

While the literature on nursing advocacy focuses primarily on advocating in particular clinical relationships between nurses and patients, some articles also address advocating—for groups of patients and the nursing profession—at an organizational and a public policy level.[11,17] This is an important kind of palliative nursing advocacy but is beyond the scope of the chapter.

Conceptual Model of Advocacy in Palliative Nursing

Six components constitute a conceptual model of advocacy in palliative nursing: clinical competence, relational care, communication skills, combined confidence and humility, interdisciplinary collaboration, and a bio-psycho-social-spiritual orientation (Figure 74.1).[18] Integration of these elements demonstrates that advocacy is a *way* of doing the things that palliative nurses do—an *approach* to care rather than a collection of discrete tasks added to an already full nursing workload. What is being advocated for is a process rather than a particular patient choice or outcome.

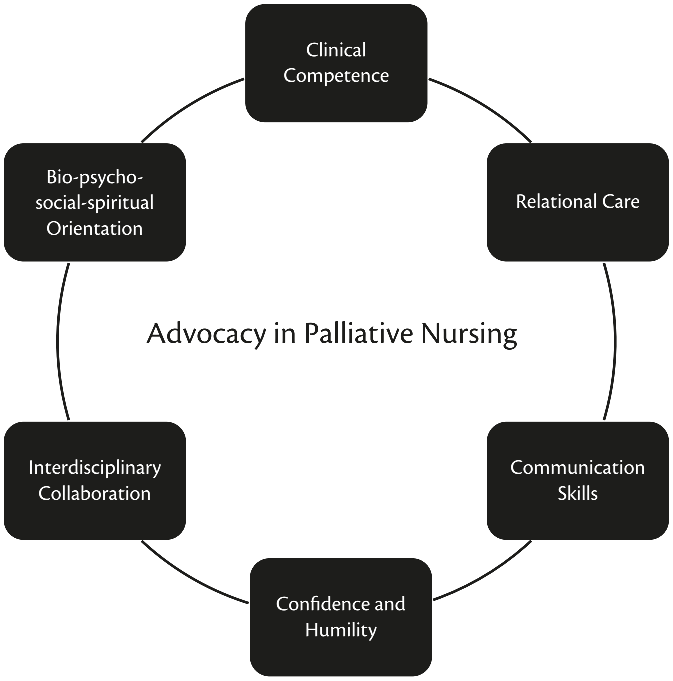
Clinical Competence
Relational Care
Communication Skills
Confidence and Humility
Interdisciplinary Collaboration
Bio-psycho-social-spiritual Orientation
Advocacy in Palliative Nursing

Figure 74.1 Core components of advocacy in palliative nursing.

Clinical Competence

"You can't practice what you don't know" has become a well-known mantra for those in the field. With knowledge and competency comes, for example, the ability to accurately assess symptom burden and functional status and intervene as appropriate, as well as to structure conversations and listen to patients in a way that identifies personal values and goals of care.[19–21] Knowledge of the current literature and best practice standards positions the nurse to make judgments about the significance of assessment findings and present such findings in a way that conveys their significance to other members of the team.[18,22–24]

Relational Care

A relational approach to nursing care emphasizes the power of therapeutic relationships between a nurse and care recipient to create an environment in which it is safe to be vulnerable and seek assistance in the midst of illness.[15,25] In this way suffering can be identified and addressed, meaning can be restored or created, and patients can integrate and express their personhood even in the midst of serious illness and injury.[26] Healing, in its broadest sense, can take place in the absence of cure. Hallmarks of relational care are empathy and reliability, in which a nurse creates an atmosphere of understanding and safety for her patient.[15] While frequently applied to environments such as long-term care facilities and patients with limited capacity to participate in their own care (such as persons with dementia), the conceptual framework of relational care is a useful one for advocacy in palliative nursing care. Creating an environment of safety and reliability allows patients and family members struggling with the impact of advanced and final illness to explore and express fears, hopes, inner conflicts, confusions, and disagreements—all of which need to be engaged and worked through to develop clear goals of care.

Nurses are usually on a unit for 8- to 12-hour periods of time, seeing patients and families on multiple occasions during each shift. Conversations will occur simultaneously with nursing assessments, monitoring and adjusting medication infusions, dressing wounds, and coordinating care. With such frequent and varied interactions, nurses build relationships with patients and families in which opportunities for observation, listening, teaching, and holistic assessment arise regularly and with less formality than with many other members of the healthcare team.[27,28] This is in addition to their more structured and formal routine assessments. Connecting with patients and families at the same time as the nurse is engaged with specific nursing interventions can open opportunities for intimacy which invite disclosure of important information. While a conversation with other disciplines may purposefully focus on a defined topic, interactions that occur spontaneously while specific nursing tasks are being performed can open a space for incidental exchanges that, while not specifically focused on clinical care, may nonetheless uncover important aspects of a person's life and the way he or she experiences aspects of illness and care that are important.

Although most of the literature on advocacy focuses squarely on advocating for the patient with little to no mention of the family, values and care preferences often take shape and are expressed in relationship with others.[29] A model of advocacy in palliative nursing that does not integrate the relational context in which life is lived is incomplete. The conceptual commitments in relational nursing have explanatory power for the therapeutic value of relationships between patients and family caregivers, not just patients and nurses. Establishing supportive relationships with family members empowers them, in turn, to maintain empathy and reliability in their relationships with the patient. Palliative care is patient- *and* family-centered care—not just one or the other.

Communication Skills

Well-developed and deliberately used communication skills enhance bedside nurses' ability to advocate for their patients and families.[30,31] Du Pré and Foster[15] explain one model of communication especially resonant with the aims of palliative care nursing advocacy: *transactional communication*. In this model, meaning is created in the shared spaces between a nurse, a patient, and family members—precisely the safe, supportive environment emphasized in relational care. Coyle and Kirk[9] offer an ethical framework for such communication guided by the cornerstone principles of clinical sensitivity, truthfulness, accommodation, and advocacy. In this framework, each communication transaction carries with it the possibility of enhancing (and the risk of diminishing) the therapeutic nature of the clinical relationship. This is done by reinforcing a commitment to honoring the moral agency of all parties and, especially, to understanding the values, preferences, and needs of the patient.[32] The potential for meaningful advocacy is advanced.

Nurses, in spending the kind of extensive time on a unit as previously described, have opportunities to interact with patients with and without family members present. It is also common for family members to communicate directly with nurses outside patients' rooms and for patients to speak with nurses when alone. The tenor of these conversations may be very different. They are considered as a whole, and yet our primary responsibility is to patients. This duality yet unity can be a difficult area for the bedside generalist palliative care nurse to negotiate. When a family prefers to communicate with the healthcare team without the patient's participation, despite their ability to engage in such conversations and decisions about care, the nurse can advocate for the patient (unless there is a strong contraindication) by moving the conversation back to the bedside and ensuring that the patient is a full participant in the process. When a patient communicates significantly different preferences in the presence of family members than are expressed when the family is not present, the nurse can explore these differences with the patient. When a nurse perceives that her patient is more confident and engaged in conversations about healthcare when a son or daughter is present, the nurse can request that critical conversations with healthcare professionals are scheduled when that person is able to participate. Hence, nurses can advocate by attending not only to the content of communication, but also to the circumstances in which communication occurs. Documentation of these conversations and interactions with the patient and family are an important part of good communication and advocacy work.[33]

Confidence and Humility

With competence comes the "power" to influence others. That power can take two forms: (a) it is empowering as a palliative nurse gains confidence in her own abilities and embraces the value of her clinical observations and findings to shape and implement the patient's plan of care, and (b) it enables the nurse to communicate information, observations, and assessment effectively.[34] Through her choice of words, confident tone, and application to the clinical context, the information she brings to the table is more likely to have an impact on the giving and receiving of care. Humility is the other face of confidence. It is the ability to be open to the views of others. Just as the nurse is confident in her skills and the value of a nursing perspective, she recognizes that she is only one member of the team and one discipline among several. The best care is delivered when the talents of multiple team members and disciplines are integrated together. By necessity, this requires acknowledging that each member of the team has a valuable—and partial—perspective when compared to the well-integrated complement of perspectives from all team members. Combining confidence with humility can enhance interdisciplinary collaboration.

Interdisciplinary Collaboration

Palliative care is, in its very nature, interdisciplinary care. Palliative nurses must not only build therapeutic relationships with patients and their families, but they are also in important relationships with other members of the healthcare team. Managing these multiple relationships, and facilitating the relationships between members of the clinical team and the patient and family, provide an important opportunity for nursing advocacy.[35] Nurses may be the ones to see most clearly how a patient/family decision is in tension with—or in direct opposition to—the best judgment of the care team. In the advocacy role, nurses can offer the team insight to the patient's and family's day-in and day-out experience of living with advanced illness and its treatment—a first-hand, lived experience for which no amount of clinical expertise can substitute. Bedside nurses may be privy to this information while other team members are not. Similarly, nurses can help patients and families understand the perspective of the team.

Bio-psycho-social-spiritual Orientation

The orientation and philosophy of nursing as a discipline is one that uses a bio-psycho-social-spiritual approach to health and illness and encourages an attentiveness to elements of patients' and families' lived experience. This includes implications of environmental, behavioral, spiritual, psychological, and social influences on advanced illness and its treatment. Addressing these elements of personal experience with patients and families, bearing witness to them, and ensuring that they are included in any interdisciplinary team discussion where treatment recommendations are being considered, is part of advocacy. Patients are considered primarily as *persons* who are also patients. Individuals and families have meaningful lives that, although impacted on by advanced illness, cannot be reduced to the biomedical aspects of disease and its treatment. By ensuring that the psychological, social, and spiritual impact of disease and treatment on patients' lives remain in the forefront of team discussions regarding care, nurses contribute a fuller picture to the team concerning this reality.[35] Presenting treatment alternatives that empower, rather than threaten, each patient's personhood is the goal.

Functional Elements of Advocacy in Palliative Nursing

Returning to the story of Mr. O'Reilly, his nurse was in a strong position to care for him in a way that illustrates seven functional elements of advocacy in palliative nursing (Box 74.1). They are highlighted in italics in the narrative that follows.

Box 74.1 Functional Elements of Advocacy in Palliative Nursing

1. Specific documentation.
2. Careful observation of patient and family interactions.
3. Assessing understanding.
4. Building rapport.
5. Eliciting care preferences.
6. Privileging patient values and preferences.
7. Teaching and sharing information.

Case Study: Advocating for a Patient—Part 2

The care team chart notes and the verbal hand-over when the nurse came on duty reflected a major concern—that the patient's real wishes around code status were being overridden by his family. The evidence cited for this was the following: (a) The patient's prior DNAR/AND choice—made several months ago as an outpatient when he was less frail and less dependent on his family, then confirmed in the emergency department just a week ago—had been changed to attempt cardiopulmonary resuscitation (CPR) during this hospitalization with the strong encouragement of his family; (b) Mr. O'Reilly, when alone with the nurse during the prior shift, spoke about not wanting to fight anymore but to be "just kept comfortable"—without pain or shortness of breath. *Specific documentation of these concerns in the electronic health record*, close review of the narrative notes from the prior day, and a thorough verbal handoff during the transition between nursing shifts ensured that this concern was communicated to the entire team and identified as an action item to be addressed with the patient and his family.

Because the nurse worked 12-hour shifts and rarely left the unit during those shifts, she was well-positioned to *carefully observe* *interactions between the patient and his family* at frequent intervals throughout the day. This was her fourth shift caring for Mr. O'Reilly, and over 40+ hours she had learned the following: (a) Mr. O'Reilly may have preferred not to be resuscitated if only considering himself. However, he had verbalized on many occasions that his family was what was most important to him. If attempting resuscitation was important to them then that might be his wish/choice now, too. He likely wanted this to be a family decision, and the team's concern that the patient's preferences were being overridden may not be warranted. (b) The patient and the family were in agreement on the overall goals of care: that Mr. O'Reilly be kept comfortable, with his symptoms well controlled, and that he be able to keep working on his almost completed book. (c) The team was on the same page with the patient and family regarding these overall goals. There was common ground.

The team felt strongly that resuscitating Mr. O'Reilly was not in his best interest. They knew that resuscitation was unlikely to be successful and, at best, would result in the patient being restored to a very compromised quality of life. By carefully listening to the patient and family, and *assessing their understanding* of resuscitation and its likely outcomes, the nurse realized that their understanding of resuscitation was very different from that of the care team. To the patient and his family, resuscitation meant restoration of the patient's ability to continue work on his book—and all of the functions/capacities required to do so.

Because she had *built a strong rapport with the patient, his family members, and other members of the care team*, the nurse had participated in discussions about code status with care team members and had been in the room when the patient was discussing code status with his family, answering some of their questions. This allowed her to see that, in both conversations, discussion of code status had become decontextualized from the overall goals of care, creating a perceived tension that arose not from actual disagreement but from discussion of this intervention absent the context of goals of care. This, in turn, had led to "resuscitation" meaning something different to the patient and his family than it did to the team. There needed to be a discussion among everyone about the likely outcomes of resuscitation and the extent to which those outcomes were consistent with the goals of care.

In reflecting on what she had observed over the past few days, the nurse realized there was a different process of decision-making within the family than there was within the care team. The family, as articulated by the son who taught decision science professionally, was resistant to prospective decision-making, preferring to integrate new information (like changes in the patient's clinical status) into their decision-making as it unfolded in real time. The team, having experienced the urgency of the situation when patients decompensate quickly and enter respiratory distress, preferred prospective decision-making as they believed there would not be time "in the moment" for the family to understand and process new information about the patient's clinical status if a resuscitation decision was postponed until the patient was in the midst of respiratory distress. The nurse saw that while the team was committed to *eliciting the patient's preferences* and *privileging the patient's values*, they were not considering that the patient and family may have a strong preference regarding *how* decisions are made.[22] She understood that the team was focused on the outcome of the resuscitation discussion in a way that neglected the significance of the process of that discussion. Because the family had strong preferences about process which were not being engaged, the outcome was elusive. As such, she advocated for a discussion process consistent with the patient's and family's preferences, educating the team about the importance of process for this patient and family.

The nurse also noted that, while the team was concerned that the patient was vulnerable to having his voice drowned out by the preferences of the family, the vulnerability of the family was being overlooked by the team. The family was in a set of conditions that was stressful in multiple ways: the family patriarch was gravely ill; they were in the environment of an academic medical center with language, customs, rhythms, and background assumptions quite foreign to them; they were being asked to make decisions in a much different style, and of a much different nature, than they were accustomed to; and they were receiving the implicit message from the team that they were doing something "wrong"—inappropriately influencing Mr. O'Reilly's resuscitation preferences.

Based on these observations, Mr. O'Reilly's nurse suggested that a discussion to clarify the question of resuscitation explicitly as it related to overall goals of care be held by his bedside and include the care team and his family. By moving the discussion to the bedside, the patient and family were able to make their perspective(s) clear to the team, including how they made decisions as a family unit and what a DNAR code status implied to them. In turn, the team was able to explain Mr. O'Reilly's current medical status and the likelihood of CPR being successful, explicitly defining "success" as it related to his values and goals. It was emphasized that the team would do whatever Mr. O'Reilly wanted once they were clear what that was.

The nurse created a set of conditions—a bedside discussion—in which the patient, family, and team could have their individual voices heard. Through active listening and sometimes reframing of the communication (message) intended and the communication (message) received, the patient, family, and care team struggled to understand each other's perspectives. The nurse frequently, and respectfully, redirected discussion back to Mr. O'Reilly's stated goals of care. Reflective listening, used by the nurse as a communication strategy, is an example of how the training and disciplinary perspective of nurses positions them strongly to be advocates.

After the bedside meeting with the team, the nurse was able to reinforce key points with the patient and his family, ensure they had some written information about resuscitation, educate the family about what was going on in Mr. O'Reilly's body to cause progressive respiratory decline, and explain to them what life was like for many patients following intubation and progression toward respiratory arrest and attempted resuscitation. Because she had cultivated respectful, therapeutic relationships with the patient and his family, and because her nursing education and experience emphasized the importance of educating patients and family members, the nurse was uniquely positioned among team members to *teach and share information* effectively.

In summary, the nurse's advocacy for Mr. O'Reilly was grounded in her palliative care competencies, attentiveness to family dynamics, observation, analysis, communication skills, and carefully cultivated relationship with the patient, family, and other members of the care team. She identified where there was agreement among the healthcare team, patient, and family regarding goals of care, and she used that as a foundation for her work. The tone of advocacy was not adversarial (us vs. them), but one of collaboration and empowerment. The nurse "took on board" the information gleaned from EHR documentation, shift handoff, and team meetings about the team's perception that the family was coercing the patient into being a full-code. But, having a certain kind of presence in the life of the patient and family and trusting her own experience/perceptions, she identified a gap between the team's perception and her own perception about the nature of the relationship between the patient and the family. The nurse's recognition of the significance of her observations to this patient's care, her documentation, and her effective communication with the healthcare team provided an additional lens through which to view the situation.[16] The confidence to trust her own assessment and recognize her value as an important member of the care team was an important component of her advocacy.

Although the nurse's advocacy work surrounding the care of Mr. O'Reilly and his family was exemplary, the need for support and mentorship is clear.[36,37] Finding a compatible mentor is not easy. Where there is an opportunity for a generalist palliative care nurse to link up with a specialist palliative care nurse—to attend team meetings with that nurse, to note how she advocates for patients and their families, and to learn how she mediates when there is disagreement among members of the care team—we encourage such nurses to do so. Debriefing with a specialist nurse following advocacy work with a patient, family, and care team creates an important space for learning and reflection—especially when a bedside nurse perceives that "things went wrong" and questions her own competency. Similarly, we encourage specialist palliative care nurses to seek out opportunities to mentor nurses at the generalist level.

Challenges and Pitfalls in Nursing Advocacy

Although the model of advocacy used for Mr. O'Reilly and his family produced an outcome that successfully engaged the perspectives and values of all parties, advocating in generalist palliative care can be quite challenging and messy. The outcome will not always be satisfying to each of the parties involved. The importance of *process* rather than outcomes is therefore stressed. In some situations, the nurse will have done her work well—identifying opportunities to empower and clarify understanding, facilitating sharing of goals and decision-making, and ensuring that the patient's voice is a strong part of discussion and decision-making—yet the outcome leaves no one feeling satisfied. Reasonable expectations regarding the ability to accurately understand the wishes of another and accepting an element of uncertainty are necessary. We put together "snapshots" of "the truth" along the way; it is a quest of understanding and a challenge, and a level of humility is required.

Indicative of the challenges that a nurse may face when advocating for a patient were *three false assumptions that became clear during Mr. O'Reilly's care:*

1. Autonomy means individual decision-making, and this family is usurping the patient's autonomy and values to accommodate their own values and needs.
2. Preferences remain stable and unchanged throughout an individual's life irrespective of changes in social situation, health status, or other situations.
3. Advocating for a particular outcome is the best approach to patient advocacy at end of life.

Engaging the six constitutive components of the model of advocacy in palliative nursing—bio-psycho-social-spiritual orientation, clinical competence, a relational approach to care, communication skills, interdisciplinary collaboration, and an attitude of confidence yet humility—the nurse was able to identify and correct each of these false assumptions in the care of Mr. O'Reilly.

Although there are many examples of challenges or pitfalls that the nurse may encounter in her role as advocate, three common examples follow. The first can arise in a relational approach to care. With frequent presence at the bedside and many interactions with the patient and/or family at a time when they can be *in extremis*, strong bonds are formed and the nurse may lose her perspective of being part of a team of clinical caregivers. Intense interactions can give rise to a protective instinct, leading the nurse to believe that she is the only one who really "understands" the patient's and family's situation. An "us" (patient/family and nurse) versus "them" (other members of the healthcare team) may be the result.[37,38] In this situation, the nurse loses her perspective and ability to be clear-sighted in effectively advocating for the patient/family as a collaborative member of the care team. The second example reverses the nurse's perceived alignment. Having shared intensely emotional and clinically challenging experiences with clinician colleagues, a nurse can develop such a strong feeling of loyalty to the team that she is inhibited from advocating fully for the patient and family. The third example occurs when the palliative nurse's orientation to advocacy is strictly a "rights advocacy" model, a model that is rooted in a response to patient vulnerability (this had originally been the focus of the team working with Mr. O'Reilly). Although the vulnerability created by severe illness is acknowledged, an exclusive focus on vulnerability, insofar as it ignores the importance of identifying and engaging patient and family strengths and competencies, can be a disservice to the patient and family, distorting the nature of their personhood and failing to engage their agency. Advocacy as empowerment, rather than doing for/in place of, is what is being encouraged in this discussion and chapter. It is a relational kind of advocacy, advocating "with" rather than advocating "for."

Conclusion

This chapter has explored what it means for a nurse to advocate for a patient with advanced, serious illness and his family members. A six-part conceptual model of palliative nursing advocacy was explained, and seven functional elements embedded in this model were illustrated in an extended case study. Nurse advocates respond to the strengths as well as the vulnerabilities of patients and families, building empowering relationships to support care decisions that respect the values and personhood of patients. Finally, common pitfalls and barriers that the nurse may encounter in his or her advocacy role were reviewed.

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CHAPTER 75

Global Palliative Care

Virginia LeBaron and Annette Galassi

Key Points

- The global landscape of palliative care is evolving rapidly as the world's population ages, more people are diagnosed with noncommunicable diseases, and technology transforms communication and how information is disseminated.
- Quality palliative care is an urgent global need, particularly in low- and middle-income countries where the burden of disease is significant but resources are often limited.
- Key factors that affect the development and delivery of palliative care in all countries include (1) shifting demographic and epidemiologic trends, (2) cultural barriers, (3) disparities in access, (4) healthcare policy and payment models, and (5) workforce shortages.
- All nurses have a role to play in global palliative care, whether they live and practice in a resource-constrained setting, travel internationally to train and support colleagues, conduct research with global implications, or advocate to reduce disparities within their local community.

Global Palliative Care: An Urgent, Unmet Need

Changing demographics, epidemiological trends, economic realities, and evolving cultural and societal norms all intersect to influence palliative care on a global scale. Worldwide, palliative care is growing, but too many countries still lack access. Millions of people experience serious health-related suffering each year (an estimated 61 million in 2015), but most never receive palliative care, especially if they live in a low- or middle-income country (LMIC).[1] The Global Atlas of Palliative Care[2] shows progress in the geographic expansion of palliative care, particularly in Africa, but full integration of palliative care services within overall health systems occurs in only 20 out of the world's 234 countries (Figure 75.1). Likewise, results from the Economic Intelligence Unit Quality of Death Report,[3] which ranks 80 countries on factors related to access to quality palliative care services, reveals stark disparities between high- and low-income countries. Encouragingly, palliative care and access to pain relief is increasingly recognized as a fundamental human right.[4] In 2014, The World Health Assembly (WHA) (the health-focused branch of the United Nations) passed the landmark Palliative Care Resolution, which officially urged member states to integrate palliative care into their national healthcare systems.[5]

This chapter recognizes that palliative care is a critical issue for all nations, but takes a particular look at palliative care in LMICs, where the greatest burden of disease often co-exists with severely constrained health resources, and where the need for quality palliative care is arguably the most urgent. An important note regarding terminology: depending on the country, palliative care and hospice can have variable meanings and be operationalized differently. For example, in the United States, the word "hospice" typically refers to a very specific package of healthcare services for patients with a life expectancy of 6 months or less. In other countries, the terms "hospice" and "palliative care" may be used synonymously, or "hospice" may refer to a specific building or location where dying patients receive care. When engaging in global palliative care efforts, it is important to clearly understand how palliative care and hospice are conceptualized and operationalized in a specific practice setting or country. For simplicity, in this chapter, we use the term "palliative care" in its broadest sense to encompass holistic care provided to patients (and their caregivers) with serious illness that has comfort and symptom control as the primary goal.

Key Factors that Influence the Global Delivery of Palliative Care

There are five key factors that affect the development and delivery of palliative care programs and services in every country, regardless of resources or income. These include (1) shifting demographic and epidemiologic trends, (2) cultural barriers, (3) disparities in access, (4) healthcare policy and payment models, and (5) workforce shortages.

The first key theme is *shifting demographic and epidemiologic trends* leading to an increased need for palliative care globally. The proportion of older people is growing rapidly, and, by 2050, the world's population aged 60 years and older is expected to reach 2 billion[6]; in fact, people aged 60 and older are the fastest growing demographic in most countries.[7] Relatedly, the number of people diagnosed with noncommunicable diseases (NCDs), such as cardiovascular disease and cancer, is also exploding.[8] NCDs are the leading cause of death worldwide, representing almost two-thirds of all deaths annually. Thirty-eight million people died from NCDs in 2012, and this number is projected to increase to 52 million by 2030.[9] These demographic and epidemiologic realities have serious implications for global health and palliative care because more people around the world will live longer with chronic illness in the coming decades.

Second, there are *cultural barriers* that hinder the development or acceptance of palliative care (see Chapter 37, Cultural Considerations in Palliative Care). In many countries and cultures, patients are not told their diagnosis or prognosis for fear it will cause

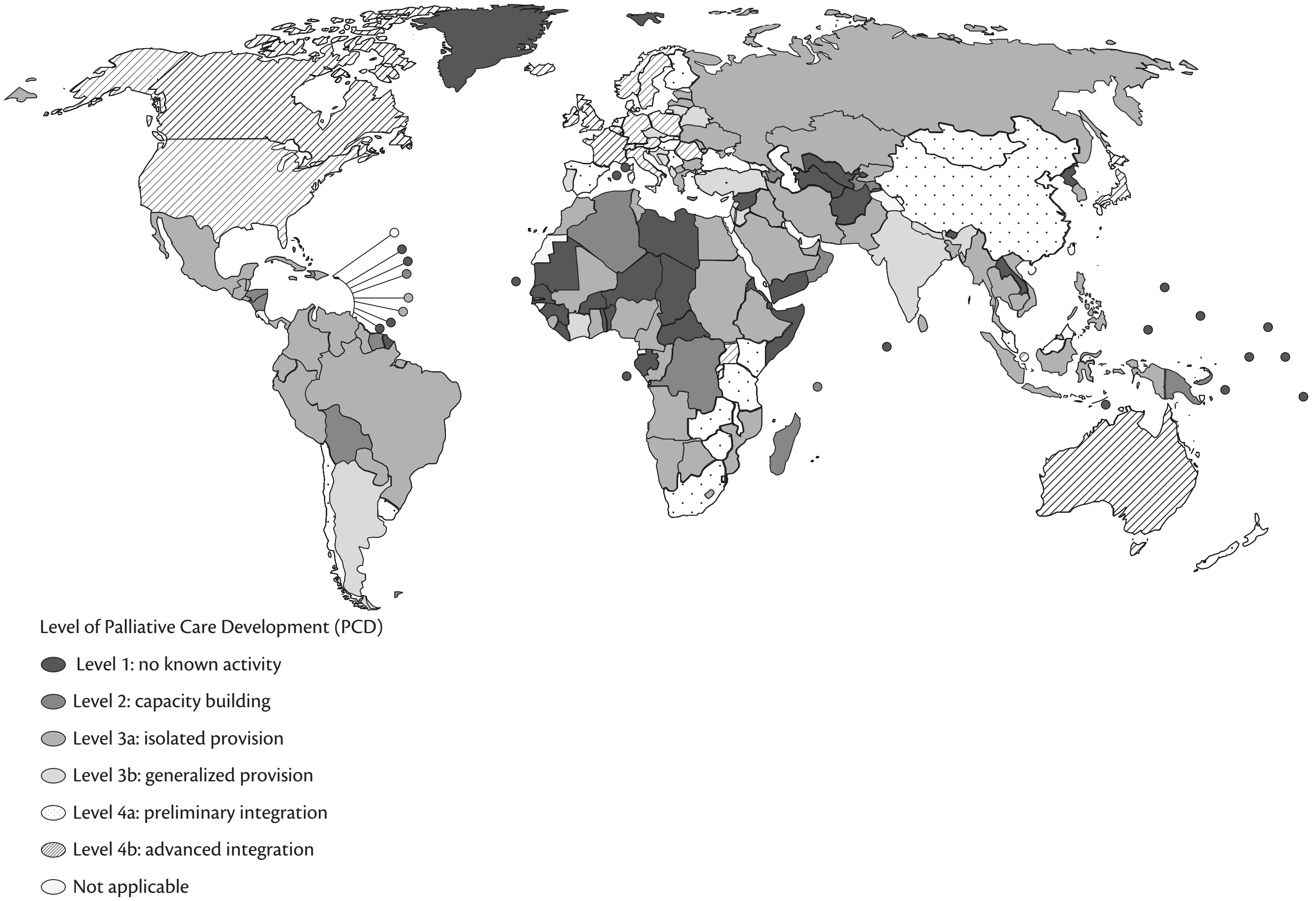
Level of Palliative Care Development (PCD)
Level 1: no known activity
Level 2: capacity building
Level 3a: isolated provision
Level 3b: generalized provision
Level 4a: preliminary integration
Level 4b: advanced integration
Not applicable

Figure 75.1 Levels of global palliative care development, 2012.
Source: Reference 2. World Hospice Palliative Care Alliance (WHPCA, 2014). Reprinted with permission,

despair and hasten death.[10] Additionally, healthcare systems and providers often emphasize "cure" without meaningful discussions regarding goals of care or quality of life. Consequently, even if palliative care services are available, they may not be initiated until the patient's last few weeks of life, if at all. For this to change, there must be a cultural shift from advocating cure-at-all-costs over comfort, greater emphasis on managing chronic illness, effective conversations about the realistic benefits and burdens of treatment, honest dialogue about prognosis, and recognition that death is an inevitable part of life.

Third, there are significant and disturbing *disparities in access to palliative care*. The vast majority of adults (approximately 80%) in need of palliative care live in LMICs; however, palliative care is underdeveloped in most of the world outside North America, Western Europe, and Australia.[11] If palliative care services do exist in LMICs, they often focus on the needs of cancer patients and may exclude patients with other chronic diseases or conditions such as congestive heart failure, chronic obstructive pulmonary disease, HIV/AIDS, dementia, neurodegenerative diseases, or drug-resistant tuberculosis. In countries where palliative care is more established, patients from racial and ethnic minority groups and lower socioeconomic status still struggle to obtain care. Palliative care also may be unavailable in rural areas, and services are often especially limited, or absent, for neonatal or pediatric patients even in high-income countries (HICs).[12]

A fourth theme affecting global palliative care development and delivery is *a country's healthcare policy and payment models*. According to the WHA, palliative care must be an essential service in a health system and part of universal health coverage of member states. A 2017 Lancet Commission report describes specific components and funding strategies for an "Essential Package" of palliative care services and urges all countries to ensure universal access by 2030.[1] In reality, only 9% of countries have advanced levels of palliative care integration into health services; all of these are HIC except Uganda.[2,11–14] When the government does not provide palliative care services, nongovernmental organizations (NGOs) such as religious institutions and philanthropic organizations often fill the void. While these groups provide momentum for the development of palliative care programs, national health systems must include palliative care as an essential service for patients with serious or life-threatening conditions in order to ensure sustainability.

Finally, perhaps the greatest obstacle to widespread implementation of palliative care services is the shortage of staff trained to provide this care. A basic working knowledge of palliative care is needed by all generalist healthcare providers (HCPs). Advanced (or specialized) palliative care skills are needed for HCPs who see a large number of patients with palliative care needs or who work in specialized palliative care settings and who train others. The attainment of basic/primary palliative care knowledge and skills can be accomplished through mandatory inclusion of palliative care in medical and nursing curricula and through continuing education programs for practicing HCPs. Programs to provide HCPs with advanced/specialist palliative care skills can be developed once basic palliative care training is established and as country or program demand requires.

Palliative care training must be adapted to the specific care context and consider available personnel and resources. HCPs in LMICs may include traditional healers, community volunteers, or community health workers (CHWs). It is vital that palliative care educational initiatives include these individuals as they may be the first, or only, HCP with whom a patient interacts. For example, CHWs in rural areas can be trained in basic palliative care skills to help identify patients in need of specialist palliative care services and then facilitate subsequent referrals.

Many small and LMIC countries cannot afford a specialized palliative care workforce, and specialty training for nurses may not exist. Barriers to training for nurses include a lack of qualified trainers, limited recognition or incentive in terms of salary or status for nurses who obtain specialization, a shortage of current and relevant print resources on palliative care, and erratic or absent Internet access which limits the utility of web-based palliative care training resources. Another key reality is the challenge of palliative care workforce "burnout," compassion fatigue, and/or moral distress, all of which can result in compromised patient care and staff attrition. Palliative care training programs and institutions should have systems in place to provide emotional support to nurses and other palliative care providers, especially in highly resource-constrained practice settings.

Many of these workforce training barriers are being addressed by international initiatives such as the End-of-Life Nursing Education Consortium Training Program (ELNEC-International) and the World Health Organization (WHO) Collaborating Centers for Palliative Care. ELNEC-International is a 5-day course that covers pain and symptom management; ethical issues; cultural and spiritual considerations; communication; loss, grief, and bereavement; and final hours of life. ELNEC-International has trained approximately 25,000 nurses and other HCPs in 98 countries.[13] WHO Collaborating Centers are designated by the WHO Director-General to carry out activities in support of WHO programs. There are currently five WHO Collaborating Centers for Palliative Care, including one nursing program, the Catholic University of Korea, College of Nursing, which is focused on the development and delivery of training in palliative care and building understanding on spirituality issues in palliative care.

Key Factors that Influence Palliative Care Implementation: Specific Challenges in LMICs

Despite the need, palliative care has only recently been recognized as a public health priority in many countries. Palliative care development using a public health framework includes four elements: (1) appropriate government policies and plans; (2) availability of essential medicines; (3) education of HCPs, policymakers, and the public; and (4) implementation of palliative care at all levels of healthcare provision.[14] Many LMICs face challenges in each of these areas.

Box 75.1 Key Elements of National Palliative Care Policy, World Health Organization (WHO)

- Service delivery through a continuum of care (through primary healthcare, community, home-based, and specialist palliative care services);
- Strategies to provide palliative care to all patients in need (noncommunicable diseases, HIV/AIDS, tuberculosis, older adults, children), with attention given to reaching vulnerable groups (poor, ethnic minorities, people living in institutions);
- Defining the government–civil society interface in establishment and delivery of care;
- Universal coverage, through financing and insurance mechanisms;
- Ensuring support for carers and families (social protection);
- Identification/allocation of resources for palliative care;
- Development of national standards and mechanisms to improve quality of palliative care;
- Identifying indicators and establishing monitoring of palliative care need and access, at national and subnational levels, including access to medicines.

Source: From Reference 16.

Appropriate government policies and plans. The provision of quality palliative care is facilitated by healthcare policies and guidelines that provide a roadmap for the development and implementation of services. Few LMICs have integrated palliative care into public healthcare policy, strategic health plans, noncommunicable disease plans, and/or cancer control plans. A national palliative care policy, whether stand-alone or part of another key health strategy, should include the essential elements outlined in Box 75.1. Government progress in addressing the palliative care needs of its citizens is often hampered by leadership changes within the ministries of health and a lack of champions able to advocate for palliative care as a healthcare priority. Another challenge is the lack of national health insurance plans in many LMICs (and in some HICs as well, such as the United States). If a plan exists, it rarely includes coverage for palliative care services.

Availability of essential medicines. National policy also affects the availability of essential medicines that are critical for palliative care. Essential medicines are defined by the WHO as medications that every country should have in adequate supply at all times, at a reasonable cost, to meet the needs of their population.[15] In 2007, the International Association for Hospice and Palliative Care (IAHPC), working in collaboration with other international stakeholder organizations, developed a list of Essential Medicines for Palliative Care (Table 75.1). Opioids are classified as essential medicines, but 80% of the world's population—the majority of whom reside in LMICs and are more likely to need palliative care due to the distribution of disease burden—lack adequate access to opioids for pain control.[1,16] In fact, more than 90% of the world's morphine supply is used by approximately 1% of the world's wealthiest countries.[17] As a result, millions suffer and die in agony without access to basic pain relief (Figure 75.2). The reasons for this are complicated but involve a combination

Table 75.1 International Association of Hospice and Palliative Care (IAHPC) list of essential medicines for palliative care

Medication	IAHPC indication for palliative care
Amitriptyline	Depression, neuropathic pain
Bisacodyl	Constipation
Carbamazepine	Neuropathic pain
Citalopram	Depression
Codeine	Diarrhea, pain (mild to moderate)
Dexamethasone	Anorexia, nausea, neuropathic pain, vomiting
Diazepam	Anxiety
Diclofenac	Pain (mild to moderate)
Diphenhydramine	Nausea, vomiting
Fentanyl (transdermal patch)	Pain (moderate to severe)
Gabapentin	Neuropathic pain
Haloperidol	Delirium, nausea, vomiting, terminal restlessness
Hyoscine butylbromide	Nausea, terminal respiratory congestion, visceral pain, vomiting
Ibuprofen	Pain (mild to moderate)
Levomepromazine	Delirium, terminal restlessness
Loperamide	Diarrhea
Lorazepam	Anxiety, insomnia
Megestrol Acetate	Anorexia
Methadone	Pain (moderate to severe)
Metoclopramide	Nausea, vomiting
Midazolam	Anxiety, terminal restlessness
Mineral oil enema	Constipation
Mirtazapine	Depression
Morphine	Dyspnea, pain (moderate to severe)
Octreotide	Diarrhea, vomiting
Oral rehydration salts	Diarrhea
Oxycodone	Pain (moderate to severe)
Paracetamol (acetaminophen)	Pain (mild to moderate)
Prednisolone	Anorexia
Senna	Constipation
Tramadol	Pain (mild to moderate)
Trazodone	Insomnia
Zolpidem	Insomnia

For complete table details, including recommended formulations and important indications for use, see: IAHPC List of Essential Medicines for Palliative Care, https://hospicecare.com/uploads/2011/8/iahpc-essential-meds-en.pdf

of restrictive regulations and bureaucracy, lack of supply, inefficient or erratic distribution and dispensing systems, limitations on prescribers, inflated medication costs, the unavailability of oral opioid formulations, and general "opioid-phobia" among HCPs and the lay public.[16,18]

At the same time opioids are unavailable in many LMICs, there is increasing alarm in some countries regarding the number of overdose deaths attributed to prescription opioids. In the United States, the so-called "opioid epidemic" has resulted in new opioid prescribing guidelines, recommended monitoring, and restrictions.[19] While it is certainly critical that safeguards exist to mitigate potential opioid-related harms, it would be a tragedy if concerns regarding the "opioid epidemic" reversed or negatively impacted decades of policy work to ensure pain relief is available to those in desperate need. A balanced approach to opioids is recommended to ensure that risks are mitigated while also ensuring access for those with legitimate medical need.[20,21]

Education of civil society. Countries need HCPs knowledgeable in palliative care to deliver services to its citizens and also to educate policymakers about the benefits of palliative care and advocate for inclusion of palliative care into health policies. Raising awareness among the lay public is also necessary to overcome stigma and misconceptions about palliative care and to create a demand for services that in turn will drive development of palliative care programs and favorable healthcare policies.

Delivery of palliative care at all levels of healthcare provision. Countries organize health services, including palliative care, at the national, provincial/state, or district level; however, services organized at the provincial or district level can result in wide variability in what is provided. In an effort to help standardize service delivery, organizations have recommended basic packages of palliative care services. One example includes the minimum package of palliative care services as recommended by the WHO[14] (Box 75.2).

It is critical that palliative care services, regardless of service delivery level, are culturally and contextually congruent. In other words, effective palliative care services must be sensitive to a country or region's societal and cultural norms; religious and spiritual practices; beliefs regarding illness, disease, and death; and expectations related to patient–family and patient–provider communication, especially regarding disclosure of diagnosis, discussion of prognosis, and delivering difficult news. Local resources, such as the availability of essential medicines, must also be taken into account. In rural areas, or in countries beginning to develop palliative care services, community-based delivery models may be more suitable and easier to implement than hospital-based models.

Implementing Evidence-Based Palliative Care Practices

The highest quality palliative care is informed by evidence and regularly evaluated. However, generating evidence and evaluating outcomes, especially in resource-constrained settings, can be hindered by a lack of trained researchers and mentors, scarce funding and resources, the inherent difficulties of conducting research with acutely ill and dying patients, lack of consensus regarding what "counts" as evidence, unpredictable infrastructure, and inadequate documentation. It is crucial that evidence used to guide palliative care practice is contextual and resource-relevant, such as when including traditional or complementary approaches to palliative care that are utilized in many LMICs. In essence, what works or is needed in an HIC, such as detailed protocols for opioid rotations or withdrawal from ventilator support, may not be feasible or helpful in a LMIC. One example of an organization actively

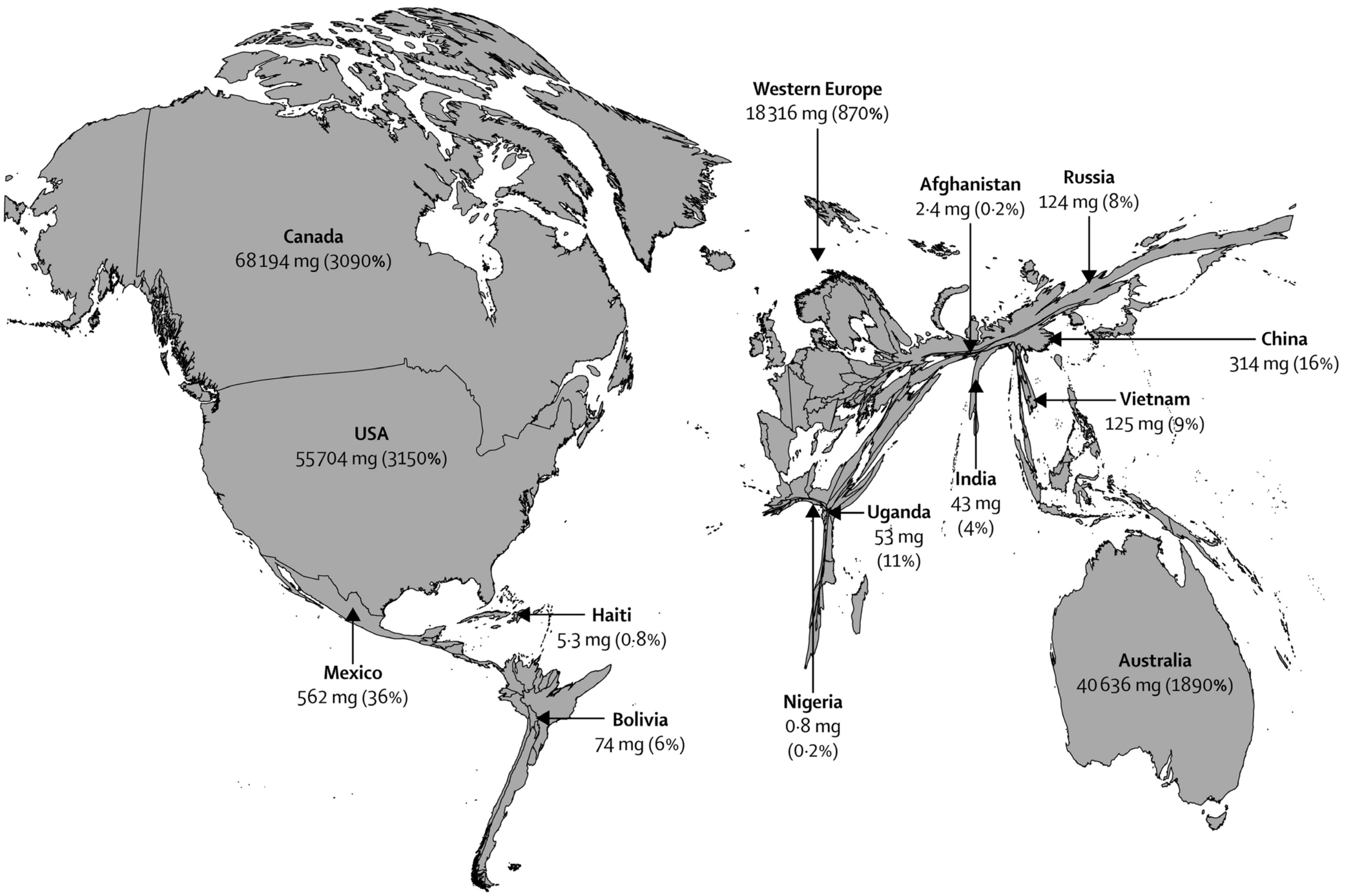

Figure 75.2 Distributed opioid morphine-equivalent (morphine in mg/patient in need of palliative care, average 2010–13), and estimated percentage of need that is met for the health conditions most associated with serious health-related suffering.

Source: International Narcotics Control Board and WHO Global Health Estimates, 2015. From Reference 1. Lancet Commission, 2017. Reprinted with permission,

working to develop palliative care evidence specific to its region is the African Palliative Care Research Network (Table 75.2).

Specific Challenges Faced by Palliative Care Nurses in LMICs

Role expectations and the status of nurses vary tremendously worldwide. In some countries, palliative care nurses independently care for patients, prescribe opioids, and are viewed as critical members of a collaborative, interdisciplinary team. In other countries, nursing is a low-status position, and nurses are expected to take a passive role in patient management and are criticized or disciplined for questioning physician orders. This can be especially problematic in palliative care, as care delivery is seriously compromised if nurses are not taught, expected, or encouraged to advocate for quality symptom management. Similarly, professional development and advanced practice opportunities for nurses in LMICs may be limited or nonexistent.

Box 75.2 Essential Palliative Care Services, World Health Organization (WHO)

- Identify patients who could benefit from palliative care;
- Assess and reassess patients for physical, emotional, social, and spiritual distress and (re)assess family members for emotional, social, or spiritual distress;
- Relieve pain and other distressing physical symptoms;
- Address spiritual, psychological, and social needs;
- Clarify the patient's values and determine culturally appropriate goals of care.

Source: From Reference 16.

Another key challenge faced by nurses who provide palliative care in LMICs involves the reality of *limited material resources and supplies*. Government/public hospitals, where the majority of the LMIC population typically seeks care, are seriously overcrowded and underresourced. Basic supplies, infrastructure (e.g., running water or electricity), essential medicines (such as opioids), and personal protective equipment may be erratically available or completely absent. Patients typically present with late-stage disease and a very high symptom burden. For example, managing large malignant wounds and extensive lymphedema is especially relevant for palliative care nurses in LMICs, but often complicated by limited resources and training.

Nurses in LMICs often face the additional challenge of caring for seriously ill patients in unstable situations. For example, nurses in LMICs may find themselves providing palliative care in

Table 75.2 Examples of international and regional palliative care organizations and key activities

WHO region/ country	Organization	Description	Activity highlights
International	International Association for Hospice and Palliative Care (IAHPC)	IAHPC works with UN agencies, governments, associations, and individuals to increase access to essential medicines for palliative care, foster opportunities in palliative care education, research and training, and increase service provision around the globe. https://hospicecare.com/home/	Maintains a global directory of palliative care services, hospices, and organizations as well as a global directory of educational programs in palliative care. Offers travel scholarships to both palliative care workers from LMICs to attend educational activities and to individuals who are invited to teach in a LMIC.
International	International Children's Palliative Care Association (ICPCA)	ICPCA seeks to achieve the best quality of life and care for children and young people with life-limiting conditions, their families, and caregivers worldwide by raising awareness of children's palliative care, lobbying for the global development of children's palliative care services and sharing expertise, skills, and knowledge. http://www.icpcn.org/	Maintains a map locating international children's palliative care organizations and services that provide palliative care for children by trained staff.
International	Worldwide Hospice Palliative Care Association (WHPCA)	WHPCA is a network of national and regional hospice and palliative care organizations and affiliate organizations that focuses on hospice and palliative care development worldwide. http://www.thewhpca.org/	Offers a palliative care toolkit for implementation in low-resource settings. Publishes a *Global Atlas of Palliative Care*, which details palliative care development and progress globally.
African Region	African Palliative Care Association (APCA)	A pan-African organization ensuring that palliative care is widely understood, integrated into health systems at all levels and underpinned by evidence in order to reduce pain and suffering across Africa. https://www.africanpalliativecare.org/	Developed the *APCA Atlas of Palliative Care in Africa*, quality standards, a core curriculum, a framework of core competencies and an advocacy toolkit for palliative care in Africa.
Region of the Americas: Latin America and the Caribbean	Caribbean Palliative Care Association (CARIPALCA)	This organization advocates on behalf of both the region and individual countries in terms of education, capacity building, research, access to medicines, linkages to other regional and international bodies, and sharing of policy initiatives.	A recently formed regional body with both health professional and civil society representation.
Region of the Americas: Latin America and the Caribbean	Asociacion Latinoamericana de Cuidados Paliativos (ALCP) (Latin American Association for Palliative Care)	A nongovernmental organization for the development and advancement of palliative care in Latin America that unites people who work in palliative care or are interested in palliative care. http://cuidadospaliativos.org/	This organization has 7 commissions including nursing and headed the development of *The Atlas of Palliative Care in Latin America* in cooperation with IAHPC.
Region of the Americas: Northern America, Canada	Canadian Hospice Palliative Care Association (CHPCA) (Association Canadienne do Soins Palliatifs)	National association that provides leadership in the pursuit of excellence in care for persons approaching death so that the burdens of suffering, loneliness, and grief are lessened. http://www.chpca.net/	CHPCA developed *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Care* which creates a shared vision and a consistent, standardized approach to the delivery of care, organizational development, education, and advocacy across Canada.
Region of the Americas: Northern America, United States	American Academy of Hospice and Palliative Medicine (AAHPM) Hospice and Palliative Care Nurses Association (HPNA) National Hospice and Palliative Care Organization (NHPCO)	Professional organization for physicians specializing in hospice and palliative medicine, nurses, and other healthcare providers. Since 1988, the Academy has dedicated itself to advancing hospice and palliative medicine and improving the care of patients with serious illness. www.aahpm.org Professional palliative care organization with a focus on supporting hospice and palliative care nurses. http://hpna.advancingexpertcare.org/ Largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. NHPCO is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones. https://www.nhpco.org/	Activities focus on education and training, resources, networking, and advocacy. An annual, interdisciplinary meeting is held each year in conjunction with the HPNA (see below). Offers a large number of educational, leadership and research resources, including opportunities for specialty nursing certification in palliative care. An annual, interdisciplinary meeting is held each year in conjunction with the AAHPM (see above). Offers a large number of educational and regulatory resources, some of which are for members only.

(*continued*)

Table 75.2 Continued

WHO region/ country	Organization	Description	Activity highlights
South East Asia Region: India	Indian Association of Palliative Care	Established in consultation with WHO and the government of India as a national forum to connect, support, and motivate individuals and institutions involved in palliative care. http://palliativecare.in/	Offers a national fellowship in palliative nursing and a distance education certificate course in essentials of palliative care. The organization's Opioid Availability Task Force is working with the Indian central government to improve opioid availability in local regions.
European Region	European Association for Palliative Care (EAPC)	A membership organization dedicated to the promotion and development of palliative care throughout Europe http://www.eapcnet.eu/Home.aspx	Developed the *EAPC Atlas of Palliative Care in Europe*. Maintains a directory of hospice and PC units in Europe by country.
Eastern Mediterranean: Lebanon	Lebanese Centre for Palliative Care -Balsam	Lebanese Centre for Palliative Care -Balsam is a NGO working in palliative care development in Lebanon and across the region through patient care, advocacy, training, capacity building, and research in PC. http://www.balsam-lb.org/index.php	Developed the *Atlas of Palliative Care in the Eastern Mediterranean Region* in collaboration with the ATLANTES Research Program.
Western Pacific Region	Asia Pacific Hospice Palliative Care Network (APHPCN)	Dedicated to promoting hospice and palliative care in Asia and the Pacific. The Network facilitates communication so that people in established hospice programs can help less experienced and more isolated colleagues. http://aphn.org/	APHPCN and the Lien Foundation (Singapore) co-developed the *Lien Collaborative for Palliative Care* to enhance palliative care leadership and capacity in developing countries. Nurses are eligible to participate.
Western Pacific Region: Australia	Palliative Care Australia	The national body for palliative care and represents all those who work toward high quality palliative care for all Australians. Aims to improve access to, and promote the need for, palliative care. http://palliativecare.org.au/	Developed *National Palliative Care Standards* to support the delivery of high quality palliative care for the person receiving care, their family, and caregivers.
Western Pacific Region: China	Chinese Association for Hospice and Palliative Care	This association offers a platform to advance the development of palliative care in China.	
Western Pacific Region: New Zealand	Hospice New Zealand	Hospice New Zealand exists to lead the hospice movement to ensure that every New Zealander has access to quality palliative care. http://www.hospice.org.nz/about-hospice-nz	Offers educational and leadership opportunities, general resources, and training scholarships for healthcare professionals with an interest in palliative care and hospice.

high-conflict settings/war zones, after devastating natural disasters, with disrupted transportation or communication infrastructure, or in the context of rapidly emerging infectious epidemics (e.g., Ebola, cholera). Each of these issues presents profound challenges and stressors for the palliative care nurse that must be acknowledged, anticipated, and managed at a systems level to ensure feasible delivery of palliative care services.

Global and Regional Palliative Care Initiatives

The Internet and mobile technology are rapidly changing the way HCPs communicate and collaborate across the globe. Palliative care providers practicing in isolated settings, or novice providers with questions, now have access to a host of resources and support, assuming they have reliable Internet service (which, of course, is not always the case). Examples of excellent, globally focused electronic palliative care resources include E-Hospice, Palliative Care Network, and Palliverse. E-Hospice (https://ehospice.com/) is a global news and information resource for those with a professional or personal interest in palliative care. Palliative Care Network (https://www.palliativecarenetwork.com/) and Palliverse (https://palliverse.com/) are interactive websites that provide opportunities to facilitate the global exchange of knowledge and ideas related to palliative care, promote collaboration among palliative care professionals, and disseminate funding opportunities.

International and regional palliative care organizations also play an important role globally by working to raise the profile of palliative care and ensure palliative care is reflected in international or regional priorities. Most of these organizations do not provide direct patient care services; instead, they focus on advancing palliative care policies, education and training, advocacy, leadership, and research. Excellent initiatives and programs have been undertaken by numerous and varied regional champions, institutions, and organizations to improve the global delivery of palliative care. It is beyond the scope of this chapter to discuss individual programs and initiatives, which are in a constant state of dynamic and rapid evolution. Instead, key international and regional palliative care umbrella organizations, summarized by WHO Regions, can be found in Table 75.2; interested readers are encouraged to explore the links for the most up-to-date detailed information and activities.

Nursing's Role in Global Palliative Care

All nurses have a role to play in global palliative care, whether they live and practice in an LMIC, periodically travel internationally to train and support colleagues, conduct research, or advocate to reduce disparities within their local community. Now, more than ever, palliative care nursing is truly a "glocal" endeavor, meaning that global issues are also local issues, and universal considerations such as access to pain relief and workforce education are interconnected and can inform each other. For example, learning about strategies to successfully deliver rural palliative care in one country can help inform effective interventions to expand palliative care services in another. This section discusses some key ways that all palliative care nurses can engage "glocally."

Training and curriculum development. The need for a nursing workforce well-versed in palliative care is paramount. At both the basic/primary level and the specialty level, nurses with palliative care and educational experience are often tapped to design and implement training programs. In many countries, palliative care education is heavily physician-/medically oriented; nurses play an essential role by creating or adapting existing curricula to ensure relevance for nursing. The most effective palliative care nursing curricula are (1) attuned to the contextual and cultural realities of practice, (2) take into account available resources and the role expectations of nurses (which can vary widely across the globe), (3) vetted by on-the-ground clinicians most familiar with the practice environment, and (4) have a plan to evaluate the impact of the training on clinical practice.

Policy and advocacy. Whether at a family or neighborhood gathering, through membership in a regional organization, or by testifying before a national legislative body, all nurses can advocate for palliative care and its crucial role within healthcare systems and institutions. Nurses contribute significantly to the advancement of palliative care each and every time they take the opportunity to dispel myths and misconceptions, advocate for its importance in policy documents (such as pain management prescribing guidelines), and accept leadership positions where they have a seat at the table to be a strong voice on behalf of palliative care and the role of the nurse.

Cultural exchange and mentorship. There are numerous opportunities for nurses to engage with palliative care providers from different countries and cultures. Traditionally, this has most often involved nurses from HICs traveling to LMICs to engage in educational or clinical practice development programs, or by partnering or "twinning" a HIC organization with an organization in another (typically LMIC) country. These experiences offer unique and potentially powerful opportunities to learn from each other, share information and strategies, and provide essential role-modeling and nurse mentorship. There is a growing awareness of the importance of the bidirectional aspect of nursing cultural exchange programs and of thoughtful participation to ensure that efforts and initiatives are optimally and mutually beneficial.[22,23]

Advocating for vulnerable populations. All nurses ideally advocate for vulnerable populations and strive to ensure equitable access to quality healthcare for all people. Perhaps nowhere is the nurse's role in advocating for vulnerable populations more vital than with patients who are seriously ill and dying. Regardless of whether nurses practice as clinicians, managers/administrators, educators, or researchers, there are many ways to alleviate suffering experienced by the most vulnerable. For example, nurses can deliver compassionate end-of-life care to populations typically unseen in healthcare systems, such as the homeless; design educational programs that include substantive content about disparities in access to palliative care and pain relief; or conduct research that aims to improve the care of seriously ill patients and their caregivers at a policy and systems level.

Conclusion

The global landscape of palliative care is evolving rapidly as the world's population ages, more people are diagnosed with NCDs, and technology transforms communication and how information is disseminated. The development of palliative care and the role of palliative care nursing, particularly in LMICs, have made significant progress in the past decade, but there is still much to be done. Too many people, especially those who are the most socially, economically, and geographically vulnerable, continue to suffer and die without access to basic palliative care services and pain relief. Continued progress will require demand from the public, advocacy from HCPs, and the political will of national governments and the global health community. Most importantly, all nurses, regardless of role or geographic location, must recognize and leverage the critical role they play in influencing palliative care on a global scale.

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CHAPTER 76

The Ethos of Palliative Nursing

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Key Points

- Palliative nursing has an ethos, a moral character, that builds meaning in the context of serious illness and death and dying.
- This moral character is defined by the qualities of a caring relationship.
- Trustworthiness, moral imagination, attending to the beauty of patients' humanity, creating a moral space in which patients can flourish, and being present with them are some of these qualities.

Case Study: The Ethos of Palliative Nursing

In the windowless hospital room lay a man dying of bone-rattling prostate cancer. The stars shined bright on the desert sky, but in this moment misery raked this man's soul. Between shallow, painful breaths, and the interludes of his wife wiping his beady brow, I asked this man to tell me his story. As a child, he was born and grew up a free man, but here lay in sharp contrast, a 61-year-old man in stateless adulthood. His childhood memories are of being with his siblings and friends, running and playing hide-and-seek in the olive trees in his grandparents' orchard. Trees even more ancient than his grandparents stood steady while war after war roiled through. Beneath the cover of night, the teenaged-man forcedly packed what cherished belongings he could carry with him and fled his homeland for a distant country not his own. As he started his trek, the man packed away some olive wood that had lain on the ground outside his house. This wood honored the lineage not just of his grandparents, and their parents, and their parents' parents, but also of all the olive trees that bore witness to his family's history.

The day I stepped into his story, he was dying—not just dying of prostate cancer but of a misery deep and untouchable by hormone therapy, steroids, opiates, or anything that we, as palliative care clinicians, have in our armamentarium to cure. Since I was a foreign, visiting scholar with a flexible schedule, I decided to sit with him and his wife for a few hours. I had nowhere else urgent to be—no beeping alarms, no intravenous line to change, no medications to give to lure me away; I had only time. And so, it was time I gave this man and his wife. My questions began by asking him about how he came to be in this country, the country of his adulthood but not of his childhood—the country of his fleeing-to but not of his rising-up-in. His story brought us to the olive groves that he lay under at night as a mere youth, looking up at the stars, more stars than he could count, stars that, to be sure, were biblical. Those ancient stars, he imparted, were the same stars King David had lain under after his anointing, the very stars that had guided the Magi to Bethlehem, the stars that Saint Paul used to navigate the road to Damascus, and the stars that the Damascenes used to travel to Mecca to go to the Holy Mosque for the Haj. After only a half hour of talking, the man's story arrived at what he wished for his final goodbye to this earth. He wanted to see those stars, the stars that observed biblical history and that had shown upon the olive trees of his youth. These ancient stars were calling him home, to his permanent home, a home beyond wars, borders, religions—a home where his ancestors dwell, a home in the stars.

To aid in his final goodbye, I secured clearance from the cancer center to take him and his wife up to the roof of the hospital one night. His pain notwithstanding, it was an ordeal. No elevator went all the way to the roof, so we had to devise a plan that included four of us carrying him up the last flight of stairs. Another helper worked to hold his urinary catheter as we executed the tactical operation. Prior to moving the patient, we placed a mattress for him to lie upon. We did it—we got him there on a stunning desert night when the stars smiled brilliantly at him. He lay there on the mattress with his wife, indulging in a talkative spurt of energy I had not hitherto seen in him. He looked upon the stars, and, in his native tongue, chattered to his wife. She gripped his hand tight, while tears were visible on her face. She did not wipe them. He could not see them as his eyes remained fixed on the stars. She listened, and cried, and held his hand tight. I understood his chattering enough to hear him say that he was ready to go; he wanted to see his family up there—in the stars. A few days later, the man died. It was a welcomed death as his pain had become unremitting. He had fallen into an obtunded state, but now he was with the stars.

Shortly after he had died, I came in and sat with him and his wife. Again, I was able to offer her time by being with her. She clutched a cross in her hands, and I could hear her praying while moving it between her fingers. The woman fell into deep sobs, convulsing in grief, so I continued to be with her. I spoke no words, but rather, I felt all I could do was witness her incomprehensible and ineffable sadness. And then, without words, she handed me that cross. She opened my clenched fingers and placed it into the palm of my hand. She looked up at me and said, "He carved it from the olive wood he took with him. I want you to have it. You are his child."

Here I had in my hand the cross this man had carved from the olive wood he had taken with him as he escaped his childhood homeland. During a war that had threatened him and his family, he still made it a point to pack this meaningful olive wood with the few belongings he was able to carry. I meditated on the cross of wood and the symbolism of the fallen branches from the trees that had looked upon his family through the centuries. The stars that had witnessed his familial history bore witness to his religious and biblical history and then, finally, to his death.

Caring for this man and his wife was the job of any palliative nurse. And, in a sense, no palliative nurse deserved such a special gift, but the token of the olive cross honored the relationship of the nurse with the patient's wife and with the patient himself. An ethics of caring is based on the notion that what it means to be a good person—a moral person, that is—has to do with the nature of relationships.[1–3] With this, what it means to be a good palliative nurse has to do with the nature of the relationships nurses develop with their patients and loved ones. This chapter will describe five qualities that are part of a caring relationship and, within the context of palliative care, form the ethos—the moral character—of palliative nursing. These five qualities are trustworthiness, imagination, beauty, space, and presence.

Trustworthiness

Trustworthiness cuts close to the heart of the ethos of palliative care nursing. Year after year, the public has rated nurses as members of the most trusted of professions.[4] Speculation on the potential reasons for the public's trust is possible, but the most obvious answer is that nurses are, in fact, trustworthy. The contemporary bioethicist Onora O'Neill has convincingly argued that trustworthiness has three components: competence, reliability, and honesty.[5]

Competency is essential for palliative nurses. This is why the Hospice and Palliative Nursing Association and the Hospice and Palliative Credentialing Center have established minimum experience and knowledge standards for achieving and maintaining certification as a hospice and palliative nurse. The contribution of competence to nursing's trustworthiness is so important that nurses work together as a community to ensure that each nurse practices safely. Nurses are each other's keeper, and the keeper of the public's trust, by working together to make sure that nurses do not harm patients. Competence also involves practicing according to the latest evidence. Nursing science contributes to trustworthiness by guiding practicing nurses through the results of rigorous science to help direct the most efficient ways to bring about patients' desired goals of care.

Reliability and competence are first cousins because a reliable nurse must first be competent. However, reliability differs from competence in that, to be reliable, nurses must do what they say they will do and be present when they say they will be present. The moral force of reliability is that patients and families can depend on what nurses say to them.

After listening to the man's stories in the case study, it is clear that the nurse wanted to give the patient a view of the stars before he died. But before the nurse asked the patient whether he wanted to see the stars one last time, the nurse had to have a way to make it happen. The nurse's own reliability and the reliability of the nurse's colleagues and the hospital would have otherwise been at stake. So, before the nurse proposed the idea to the patient and his wife, the nurse would have first had to check with colleagues and nursing administration. The hospital administration's embrace of the idea was dim, but administration understood the importance of the unusual plan for the patient's and his wife's wishes. If the nurse had mentioned the plan to the patient and his wife before the nurse had done this homework, the collective reliability of the nurse, the nurse's colleagues, and the hospital would have been on the line.

The palliative nurse also understands that reliability entwines with *honesty*. A nurse's word, to a large degree, verbalizes her or his reliability. In the context of healthcare, honesty, O'Neill suggests, is not just keeping one's word, but ensuring the absence of deception. When patients and families ask questions for which there is no easy, straightforward answer, it is dishonest for nurses to pretend there is an answer. No medication guarantees a relief of the patient's symptoms—remember that science traffics in probability, whereas treatment plans favor the odds, rather than guarantees, of success. Based on scientific testing, the probability of a medication's efficacy for relieving a symptom may be in the patient's favor, and that is exactly how nurses need to respond to patients' questions. However, in the end, the medication may not relieve the patient's symptom. The medication or treatment may fail to work as science suggests it does. Explaining efficacy of medical options should guide nurse–patient communication and will aid in rationalizing why a palliative care team may have to move on to other modalities to attempt symptom relief. The sake of honesty further demands not deceiving patients and their families. Nurses practice in very few certainties other than the singular idea that each human, including the nurse herself, shall one day die. Honesty with patients and their families rests in nurses' acknowledging that there are no certainties. Nurses cannot deceive patients and their families by withholding information or deceiving them with fake certainties. Rather, being present with them in the indeterminacy of pain and suffering and dying is how nurses do not deceive patients and families.

Imagination

The second quality of a caring relationship is imagination. Often, not having straightforward answers to medical and spiritual issues overwhelms those in palliative nursing. All nurses have had patients who, before they die, have one last desire that seems impossible to achieve. These situations demand imaginative thinking. The eighteenth-century philosopher, Immanuel Kant, believed that imagination takes an individual back to "first principles," meaning that imagination brings one back to what matters most and what is most fundamental.[6]

In the case study, imagination was necessary, as the nurse knew that the patient could not be taken back to his grandfather's olive trees; the patient was too sick to transport that far. Whatever the nurse could do for the patient had to be imagined right where the patient was. The nurse's colleagues, the hospital administration, and the nurse had to think new thoughts about how to take the patient back to those memories of lying under the trees and looking up at the stars. They had to use their imaginations to devise a plan to get the patient as close to that experience as possible.

Imagination as described here is deeper than just devising a creative plan to achieve a desired result. Moral imagination means that nurses can *feel with* their patients and their families. This does not mean that, through empathy, nurses must suffer the same as patients and families suffer. However, it does mean that nurses have to feel, or sympathize, with how important goals, beliefs, and practices are to patients and families. Nurses must work to feel the depth of whatever brings their patients meaning, purpose, peace, and comfort as they face serious illness and even death. This feeling—a feeling named here as *compassion*, a feeling of caring for what matters to others who suffer—gives nurses the energy to think creatively about how to help patients and families achieve their goals. Furthermore, compassion aids nurses in being faithful to patients' and families' beliefs and practices when the odds are against them. Compassionate imagination gives one's creative solutions legs, not just by thinking about innovative solutions to achieve patients' and families' goals, but compassionate imagination requires actively working to bring that solution to fruition. By engaging in imaginative solutions to seemingly intractable problems, nurses see the humanity of their patients. Humanity is, after all, beautiful.

Beauty

Beauty is another quality of a caring relationship: seeing the beauty of patients' humanity. The first way to honor patients' beauty is to listen to them. Not only is listening the process of relationships, according to the contemporary moral psychologist Carol Gilligan, but listening is the only way a provider can discover who patients are and what matters to them as they face serious illness.[7] Furthermore, what is distinctive about the beauty of humanity is that humanity can be injured. "Injury," the contemporary scholar of aesthetics, Elaine Scarry, says, is the opposite of beauty.[8] And yet, if, *per impossibile*, someone were invulnerable to injury, by definition he or she would be incapable of being beautiful. Being beautiful is being open to injury, even though injury is a wrong, as Scarry notes. Serious illness is a wrong in that it opens individuals up to injury by directly challenging their humanity. But amid the injury of serious illness, listening to patients is actively restorative. Listening is the succor that restores their humanity in face of the injury of serious illness. While actively listening, the nurse ceases to be the nurse, the healthcare provider, the medication prescriber, the Other; rather, the nurse becomes a person listening to another person, listening to the other's joys and sorrows, reminiscences and regrets, hopes and fears. When actively listening, nurses treat their patients not as patients but as people who, though sick and dying, are alive.

The man dying of prostate cancer, in a country not his own, was foreign to the nurse. The nurse could speak the patient's tongue grammatically, but only a native speaker who had shared the culture and experiences of this patient could so easily share the unspoken symbols of the language. Although the physical language was understood, the underlying humanity brought from the historical culture of the language could have been easily lost in translation without the nurse's actively listening. It was active work for the nurse to sit and listen to the patient's stories through this foreign tongue. Nurses may not immediately fully understand their patients because of a lack of shared experiences or culture. After listening to a few stories, though, surely nurses can find deep commonalities and connections. More profoundly, humanity is shared by all; this is a commonality between nurse and patient; everyone shares the same nature: human nature. When nurses listen deeply enough, they hear their own humanity in others' stories. In hearing one's own humanity in others, one can then feel the compassion that motivates imagination.

The realities of modern nursing, however, conspire against imagination. Nurses do not have time to sit and listen to patients for hours, much less minutes, on end. Nurses are busy, and the demands of the modern hospital, clinic, and hospice restrict their time. That said, nurses also know from experience that it does not take all that long to listen. A few minutes, sitting down, being attentive, not using the precious time with one's own words, but being aware of patients' words and of their emotions as they speak them: this is listening. Present, attentive listening is the kind of listening that restores beauty even as disease and death injure.

Space

In the modern medical industrial complex, patients present to nurses with their humanity injured by serious illness. Some patients present to the nurse dying. The humanity nurses aim to restore through caring relationships may be injured even more by the public spaces of the hospital, the clinic, and the hospice. This includes the machines that make it possible for nurses to deliver quality symptom management. Even when patients present in their homes, nurses bring with them the paraphernalia of the medical complex: the hospital beds and the equipment and machines that would never otherwise be in their homes.

One quality of a caring relationship is to create the space, in the context of the impersonal medical industrial complex, in which patients can still be themselves.[9] Of course, this is not simple. By being trustworthy with their patients, by imagining what needs to be done to fulfill patients' goals, by being faithful to who patients are, and by active listening, nurses open up the space for patients to be who they are—undefined by serious illness. This is part of the reason to become a palliative nurse: to treat patients as the people they are, to provide them the space to be who they are, even as serious illness imperils or takes their lives. For many palliative nurses, it is what sustains them: that moment when they see a smile shine through, a laugh, the confession of fear, the expression of hope, and the stories of a beautiful life. When nurses care that they are trustworthy, imaginative, and listen to find the beauty of their patients' stories, they then open up the space in the context of serious illness for their patients to be present as themselves.

Presence

To be trustworthy with patients, to offer imaginative responses, to listen to stories, to create the space for patients to be themselves in the clinic or their home, nurses must be present. Being present is another quality of a caring relationship. *Presence*, in the context of palliative nursing, is not nurses adopting a power pose by which to assert themselves and their desires upon patients and families. Presence is, rather, being with patients and families not as cases but as people. When in the presence of other people, nurses respect patients' capacity to make their own decisions and to be in relationships.[10]

The capacity to make decisions is essential to what it means to be a person. There are often circumstances where the nurse may not understand, or even agree with, every decision the patient makes. For instance, the patient's disease may be progressing with every evidence-based treatment already utilized, but the patient still may want to "keep going." There are infinite reasons why a patient may choose a particular decision or course of action, and the patient may need psychological or spiritual support to come to terms with said reasons. A nurse must not take away the patient's capacity and ability to make decisions about his or her own care, lest the nurse take away the patient's personhood. By taking away personhood, the nurse ceases to be in the presence of this human, and, therefore, the ability to be in a caring relationship with this person ceases. For a palliative nurse, this is simply untenable. For palliative nursing, the quality of presence is to be in the presence of a person who makes decisions about his or her own life.

The quality of presence includes respecting people's capacity to be in relationships. Patients have the capacity to choose with whom they want to be in relationship—including the nurse. Remember, patients come with their own histories around relationships, which may include traumatic relationships. Nurses must be open to patients choosing, or not choosing, to be in relationship with them. If the choice is the latter, it does not negate the role of the palliative nurse. It means, rather, that the nature of the nursing arrangement with the patient becomes more task-oriented. Yet, the nurse, through mindful presence, can still look for moments when the patient is open to relationship. It is in these moments that patients and nurses are present with each other and can make meaning in shared experiences.

The authors believe that that is what happened with the man who died of prostate cancer and with the nurse in the case study. The patient opened himself up to having a relationship with the nurse, even though he had only come to know the nurse in the last few days of his life. It is uncertain whether the patient made some meaning out of his and the nurse's relationship, but it seems as if he did. He asked his wife to give the nurse the cross the patient had carved out of the wood he had carried with him from the land from which he had long ago been dispossessed. Nor do we know whether the nurse made meaning out of her relationship with the patient and his wife. This gift of presence, however, gave the nurse the opportunity to become a better person, if only by learning to be open to having a relationship with people who seem far from one. The quality of presence is the quality of being open to the choices of patients, including their choices to make meaning out of illness with the nurse by their side. By being present to them—ready for them to choose to be in relationship—the nurse remains open to her or his own growth.

Palliative nursing demands much from nurses; it taxes emotions and spirits. However, if nurses attend to the qualities of a caring relationship through the five qualities articulated here, then the unexpected creation of meaning in the context of relationships with other people for whom nurses care becomes the ethos that carries nurses through these difficulties. These five qualities of a caring relationship—trustworthiness, imagination, beauty, space, and presence—help guide the palliative nurse to honor the humanity of his or her patients and his or her own humanity, too. There surely are other ways of articulating these and other qualities via serendipitous creativity,[11] which is an openness to the new meaning one can create in caring for the sick and the dying. But this is what the authors take the ethos—the moral character—of palliative nursing to be: that nurses are in caring relationships with their patients.

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Index

5HT3 receptor antagonists, 150, 155–156, 195
5HTP, 366
12-step programs, 527

AAHPM. *See* American Academy of Hospice and Palliative Medicine
Abdominal planes, 275–276
Abnormal movements, 291–297
Abuse of substances. *See* Addiction; Substance use disorders
Academic Consortium for Integrative Medicine and Health, 361
Acceptance and commitment therapy (ACT), 315
Access to healthcare, 714, 800–804
  definition, 800
Accomplishments, 822
Acetaminophen, 118, 119*t*, 778
ACP. *See* Advance care planning
ACS. *See* Anorexia/cachexia syndrome
Active dying. *See also* Death and dying
  assessment during, 49–53, 50*t*, 51*t*
  death rituals, 425–427
  fever and, 288, 423
  symptoms, 50*t*
Active euthanasia. *See* Assisted dying
Activities of daily living (ADLs), 684–685
Acupuncture/acupressure, 126
  for gastrointestinal symptoms, 366
  for mood and sleep, 366
  for nausea and vomiting, 158–159
  for pain management, 364
Acute pain, 99. *See also* Pain
Addiction, 106–107. *See also* Substance use disorders
  relapse prevention, 525–526
  treatment for, 525
Addiction Behaviors Checklist (ABC), 526
Adjunct analgesics, 125
Adjuvant analgesics, 123–125, 124*t*
Adolescents, 783–789. *See also* Children and adolescents
  developmental stage, 783–784
  grief and bereavement, 784
  in hospice care, 803
  interactions with healthcare providers, 788
  living in two worlds, 786
  spirituality and, 786–788
Adsorbent agents, 199
Advance care planning (ACP), 79–85
  background, 79–80
  case studies, 81–82*c*, 84*c*
  communication on, 66–67, 66*b*
  consensus definition, 80*b*
  continuum, 81*f*
  definition, 80
  documentation, 80
  EOL decision-making and, 84
  evolving choices in, 421–422
  family caregivers and, 415–417
  heart failure and, 567
  HIV/AIDS and, 517
  at hospital admission, 84
  nursing roles in, 84–85
  patient values and, 81
  pediatric, 743
  process, tools and strategies for, 81–84
  recommendations on, 691–692
  reimbursement for, 693, 814
  target population, 81
  treatment preferences, 81
Advance directives (AD)
  assessment and, 39
  communication on, 66*b*
  compared to POLST, 84*t*
  completion of, 82–83
  definition, 691–692, 743, 826
  in electronic medical records (EMR), 26
  HIV/AIDS and, 517
  hope and, 383
  palliative sedation and, 357
  psychiatric patients and, 510
Advanced certified hospice and palliative nurses (ACHPN), 813, 851
Advanced Illness/Palliative Care (AIPC) program, 675
Advanced Palliative Care Certification (TJC), 5*b*, 9, 21, 621, 811–812, 844
Advanced practice registered nurses (APRN), 809–815
  billing and reimbursement, 616–617, 813–814
  case studies, 815*c*
  certification, 813
  clinical experiences for, 813
  in community-based palliative nursing, 616
  competency, 812
  Consensus Model for regulation of, 809–812, 814–815, 848
  continuing education, 813
  education and training, 812–813, 848
  guidelines and standards of practice for, 10
  historical background, 809–811
  in hospital-based palliative care programs, 22
  outcomes of care, 813
  role on interdisciplinary teams, 91
  in rural palliative care, 676
Advocacy in palliative nursing, 861–866
  bio-psycho-social-spiritual orientation, 864
  case studies, 861*c*, 864–866*c*
  challenges in, 866
  clinical competence and, 863
  communication skills and, 863–864
  conceptual model, 862–863
  confidence and humility in, 864
  functional elements of, 864–866
  interdisciplinary collaboration, 864
  relational care and, 863
Affordable Care Act. *See* Patient Protection and Affordable Care Act of 2010
African American populations, 469, 470*t*
  health disparities, 500
  medically administered nutrition and hydration use among, 213
  pain management, 479, 525
  poverty among, 491
  in rural areas, 676
  spirituality, 787
Age considerations, 473–474. *See also* Adolescents; Aging; Children and adolescents; Developmental stages; Older adults
Agency for Healthcare Research and Quality (AHRQ), 573
Aggression, mental illness and, 510–511
Aging, 484–486. *See also* Age considerations; Older adults
  dysphagia and, 167
  HIV and, 515
  Medicare and, 15
  in United States, 483
Agitation and restlessness, 319–327
  dehydration and, 209, 210
  in intensive care units, 627–629
  nonpharmacological management, 628
  pharmacological management, 627, 628*t*
AIDS. *See* HIV/AIDS
Airway clearance techniques, 171–172
Alaska Natives. *See* American Indians/Alaska Natives
Albumin, 40
Alcohol use disorders, 522. *See also* Substance use disorders (SUD)
Alcoholics Anonymous (AA), 37
Algor mortis, 428
Algorithms, for quality improvement, 581–582
Allow Natural Death Orders, 67
  definition, 737*b*
Alprazolam, 156, 314

ALS (Amyotrophic lateral sclerosis), 298–299, 300*t*
  dysphagia resulting from, 163, 166
  nutrition considerations in, 144
  sialorrhea and, 177
Alternative medicine, 362. *See also* Complementary and integrative therapies
Alvimopan, 191
Alzheimer's disease
  dysphagia resulting from, 167
  pain management and, 111
  sialorrhea and, 177
AMA. *See* American Medical Association
Ambien (zolpidem), 335
Ambulatory palliative care teams, 89, 95
Ambulatory settings, 639–648
American Academy of Hospice and Palliative Medicine (AAHPM), 5*b*, 9, 20
  advocacy information online, 804
  on feeding tubes, 167
  National Consensus Project and, 811
  nursing education and, 844
  online resources, 675
  on quality standards, 577, 619
American Academy of Neurology, 9*b*
American Academy of Pediatrics, 713, 737, 749, 753, 758, 800
American Academy of Sleep Medicine, 330, 333
American Association for Critical Care Nurses, 833
American Association for Respiratory Care (AARC), 172
American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR), 220
American Association of Colleges of Nursing (AACN), 10, 692, 812–813
  palliative care education, 844
American Association of Nursing Homes, 607
American Association of Retired Persons (AARP), 675
American Board of Hospice and Palliative Medicine (ABHPM), 20
American Board of Medical Specialties (ABMS), 6, 19, 620
American Cancer Society (ACS), 493–494
  on cancer-related fatigue, 133
  public policy and, 29
American College of Chest Physicians, 833
American College of Physicians, 629
American Heart Association, 9*b*, 827
American Indians/Alaska Natives, 469, 470*t*
  Hopi Indian mourners, 392
  neonatal palliative care and, 752
  soul injury rituals, 542
American Medical Association (AMA), 693, 737, 838
American Nurses Association (ANA), 6, 10, 149, 813
  on advance care planning, 84
  Code of Ethics, 55, 746
  on communication, 55
  on end-of-life decision-making, 70
  on ethical considerations, 834
  on nursing education, 845
American Nurses Credentialing Center, 813
  Magnet Status Recognition Program, 10
American Pain Society Patient Outcomes Questionnaire-Revised (APS-POQ-R), 109
American Society for Pain Management Nursing (ASPMN), 100, 110
American Society of Clinical Oncology (ASCO), 9, 27, 149, 156–157
  on chemotherapy-induced neuropathy, 533
  depression and anxiety guidelines, 310
  opioid use guidelines, 526
  on palliative care, 692
  on pulmonary palliative care, 552
American Society of Nephrology, 9*b*
American Stroke Association, 9*b*
American Thoracic Society (ATS), 552–553, 883
Amyotrophic lateral sclerosis. *See* ALS
ANA. *See* American Nurses Association
Analgesics, 195–196. *See also* Opioids; Pain management; *specific medications*
  "causing" death, 627
  ventilator withdrawal and, 630–631
Ancillary disciplines, role on interdisciplinary teams, 92, 94*c*
Anorexia/Cachexia Subscale (A/CS), 143
Anorexia/cachexia syndrome (ACS), 140–146
  assessment of, 142–143, 143*b*
  case studies, 145–146*c*
  definition, 140
  intervention and treatment for, 143–145
  medically administered nutrition for, 207
  multimodal approach, 145, 146*b*
  pathophysiology of, 141–142, 141*t*
  pharmacological interventions, 144–145, 145*t*
  psychosocial support for, 145
  symptom management in, 143
  terminology in, 140, 141*t*
Anticholinergics, 195, 199, 210, 225, 324, 335, 662
  constipation resulting from, 187*b*
  for nausea and vomiting, 156
Anticipatory grief, 44, 341, 393–394, 724, 784
Anticipatory nausea and vomiting, 150, 159
Antidepressants, 312–314
  for anxiety, 335
  for insomnia, 335
  for pain management, 123, 124*t*
Antidiarrheal medications, 199–200
Antiemetics, 154–157, 154*b*, 194–195
Antiepilepsy drugs, 123, 295*b*
Antifungals, 248
Antihistamines, 210
  for insomnia, 335
  for nausea and vomiting, 155
Anti-inflammatories, 199
Antimuscarinic medications, 225
Antipsychotics, 504–507, 510
  for anxiety, 314
  for delirium, 324–325
  for insomnia, 335
  for nausea and vomiting, 155
Antiretroviral therapy, 142
Antisecretory agents, 195, 199
Antisocial personality disorder, 508
Anuria, 231
Anxiety, 309–317
  assessment and screening considerations, 47, 47*t*, 269, 310–311
  bereavement and, 391
  in caregivers, 632
  communication and, 60
  diagnosis, 311–312
  DSM criteria for, 311
  integrative therapies, 315
  in intensive care units, 627–629
  nonpharmacological management, 628
  personality disorders and, 508
  pharmacological management, 313–314, 627, 628*t*
  prevalence, 309, 310*t*
  psychotherapeutic interventions for, 314–315
  treatment, 312
Appetite, 140–146, 206, 214, 704–705
Aprepitant, 156
APRNs. *See* Advanced practice registered nurses
APS-POQ-R (American Pain Society Patient Outcomes Questionnaire-Revised), 109
Armed forces patients. *See* Veterans
Arnica gel, 365
Aromatherapy, 126, 701–702
  for mood and sleep, 365–366
  for nausea and vomiting, 158*t*
  for pain management, 364
Art therapy, 361
Artifacts, communication and, 56
Ascites, 200–203, 664
  assessment, 200
  case studies, 200*c*, 202*c*
  definition, 200
  diagnostic paracentesis and laparoscopy, 201
  diagnostic studies, 201
  imaging studies, 201
  management, 201
  nursing interventions, 201
  pathophysiology, 200
  pharmacological management, 201
  physical examination, 200–201
  prevalence, 200
  procedural and surgical management, 202
Asexual populations. *See* LGBTQIA (lesbian, gay, bisexual, transgender, queer/questioning, intersex, and asexual) populations
Asian/Pacific Islander populations, 469, 470*t*, 479
  medically administered nutrition and hydration use among, 213
  poverty among, 491
Aspirin, 118, 119*t*
Assessment. *See also* Pain assessment; Patient and family assessment; Spiritual assessment
  definition, 101
  importance of, 273
Assisted dying, 837–841. *See also* Euthanasia; Physician-aid-in-dying (PAD); Physician-assisted suicide (PAS); Withdrawal of life-sustaining treatments
  alternatives to, 841
  assisted suicide, 830
  case studies, 840*c*
  definitions, 837
  ethical and legal issues in, 357, 830–831, 839–840
  global perspectives on, 837, 838
  history of, 837–838
  nursing responses to requests for, 841
  reasons for, 840–841
Assisted living facilities (ALFs), 606, 616
Association for Benchmarking Health Care, 581
Association of Pediatric Hematology/Oncology Nurses (APHON), 737
Ataxia, 349
Attentional fatigue, 136
Atypical antipsychotics, 155
Australia/New Zealand, 6
Automatic referrals, 23
Autonomy, 211, 357, 621, 834. *See also* Self-determination
  assisted dying and, 839–840
  cultural considerations and, 478–479
  life-sustaining treatments and, 629

  loss of, 830
  in nursing homes, 608
Avoidant personality disorder, 508
Ayurvedic medicine, 362

Babinski sign, 295
Baclofen, 124t, 125, 296
Bacterial enterocolitis, 196
Bad news discussions, 68–69, 69b
Balanced Budget Act of 1997, 677, 814
Barber case, 211
Barbiturates, 358
Barriers, 16–17
  to communication, 58–59
  in emergency department (ED), 653–656
  in global palliative care, 868–874
  to hospital-based palliative care (HBPC), 16
  in nursing education, 848–849
  to pain assessment, 99, 100b, 101t
  to pain management, 116, 117b
  in pediatric palliative care, 712–715
  in poor populations, 496–497
  in rural palliative care, 672–673
  severe and persistent mental illness (SMPI) and, 503–504
Baseline/Transitional Dyspnea Index (BDI/TDI), 220
Beauty, 450, 879
Becker muscular dystrophy, 304
Behavior Pain Assessment Tool (BPAT), 625
Behavioral interventions. *See also* Cognitive-behavioral therapy (CBT)
  delirium and, 326
Behavioral Pain Scale (BPS), 112t, 625
Belgium, 838
BELIEF spiritual assessment model, 436t
Benchmarks, for quality standards, 581, 619, 811
Beneficence, 211, 357, 839, 856
Benner Novice to Expert Framework, 10
Benoliel, Jeanne Quint, 844
Benzodiazepines (BZD)
  for anxiety, 314
  for bipolar disorder, 507
  for delirium and, 324–325
  for dyspnea, 702–703
  for insomnia, 335
  in intensive care unit, 627
  for nausea and vomiting, 156
  in outpatient palliative care, 646–647
  pain assessment and, 625
  palliative sedation, 358–359
  ventilator withdrawal and, 631
Bereavement, 390–401. *See also* Grief; Loss; Mourning
  child's death and, 400, 724, 729–730, 758–770
  complicated, 52, 52b, 394
  continuing bonds with deceased, 399–400, 796
  cultural influences on, 391–392
  definition, 390, 759
  duration of, 399
  family dynamics in, 400
  grief and, 390, 392–396, 397b
  hospital-based services, 768
  "letting go" process in, 399
  nursing roles, 764–770
  process of, 390–391
  resources, 769b
  support in, 396–401, 633
  for veterans and their families, 543–544
Bereavement coordinators, 91, 94c
Bereavement excursion, 393
Bernard Osher Foundation, 362
Beth Israel Medical Center (BIMC) pilot study, 588–605f
Bifidobacterium, 192
Biliary obstructions, 663–664
Billing and reimbursement, 616–617, 693, 813–814
Bioelectrical impedance analysis (BIA), 243, 245f
Biofield therapies. *See* Energy therapies
Biological therapies, nausea and vomiting treatment, 158
BIPAP (Bilevel positive airway pressure), 371, 373, 554–555
Bipolar and related disorders, 321, 506–507
Bisexual populations. *See* LGBTQIA (lesbian, gay, bisexual, transgender, queer/questioning, intersex, and asexual) populations
Bisphosphonates, 124–125, 351–352
Bladder management, 230–236
  bladder disorders and emergencies, 233–235
  case studies, 232c, 233c
  psychosocial factors and care environment, 235
Bleeding, 257–258, 270b
  hemoptysis, 347–348, 349t
  interventions for, 261f, 261t
Blogs, 791–795
  illness blogs, 793–795
BODE index, 556
Body image, 200, 251, 257, 268, 275, 338–339, 532
Body monitoring, 821
Bone metastasis, 352–353
Borderline personality disorder (BPD), 508–510c
Borg scale, 220
Bowel management, 186–203
  ascites, 186, 200–203
  constipation, 186–192, 203
  diarrhea, 186, 196–200, 203
  malignant bowel obstruction, 186, 192–196, 203
BPI-SF (Brief Pain Inventory-Short Form), 108–109
Braden Scale, 260
Brain death, organ donation after, 548–549
Brain tumors
  dysphagia resulting from, 165
  seizures and, 291
Breakthrough medications, 26
Breast cancer
  hypercalcemia and, 350
  lymphedema and, 242t, 244
  malignant fungating wounds, 268
  radiation dermatitis, 271–272, 271f, 272f, 272t
  substance use disorders and, 524c
Breathing, 217–226. *See also* Mechanical ventilation (MV)
Breathlessness. *See* Dyspnea
Breen School of Nursing of Ursuline College, 812
Brief Pain Inventory-Short Form (BPI-SF), 108–109
Brokenness, 459–460
Buddhism, mourning in, 392
Bulk effect of wounds and dressings, 255, 258
Bulk laxatives, 189
Buprenorphine, 121
Burdening, of caregivers, 408–409
Burnout, 634, 819–820, 822b, 834
Butyrophenones, 155

Cachexia. *See also* Anorexia/cachexia syndrome (ACS)
  heart failure and, 566
CACP. *See* Center to Advance Palliative Care
C-ACS (cancer-related anorexia/ cachexia), 140, 143–144
CAGE questionnaire, 523, 524
Calcinosis cutis and calciphylaxis, 270–271
Calcitonin, 124t, 125, 352
Calcium channel blockers, 124t
Calcium levels, 350–352
Calendula *(C. officinalis),* 367
California, 837
  hospice policy, 801
California Healthcare Foundation, 690
A Call for Action—Nurses Lead and Transform Palliative Care (ANA and HPNA), 10
Canada
  assisted dying in, 838
  homeless populations, 492, 499
  palliative care guidelines, 6
  Royal Victoria Hospital, 15
  rural palliative care, 676
  Rural Palliative Telehealth Project, 674–675
Cancer. *See also* American Society of Clinical Oncology; Cancer survivorship; Cancer-related Fatigue (CRF); Chemotherapy; National Comprehensive Cancer Network (NCCN); Radiation therapy; *specific types of cancer*
  bleeding etiologies, 270b
  bone metastasis and pathological fractures, 352–353
  case studies, 272c
  in children, 803
  clinical trials for, 666, 741b
  diarrhea and, 197
  dysphagia resulting from, 165–166
  fistulas and, 272c
  homelessness and poverty, association with, 492–493
  lymphedema and, 238, 244, 244–245c
  metastatic, 252c
  opioid medications for, 527
  outpatient palliative care and, 644
  pain resulting from, 99c, 269, 780–781
  pediatric, end-of-life decision-making and, 736–747
  pediatric decision-making, 741–743
  race/ethnicity and, 493–494
  trajectory of, 32, 48
Cancer survivorship, 530–536
  assessment of symptoms, 532–533
  case studies, 532–536c
  communication considerations, 535
  depression and, 533
  existential concerns, 534–535
  mood disorders and, 309
  nonpharmacological management, 535
  palliative care and, 530–532, 536
  social considerations, 534
  spirituality and, 534–535
Cancer-related anorexia/cachexia (C-ACS), 140, 141t, 143–144
Cancer-Related Fatigue (CRF), 132–138, 133b, 532–533
Cannabinoids. *See also* Marijuana
  for anorexia/cachexia syndrome, 144–145

Cannabinoids (*Cont.*)
  delirium and, 324
  for nausea and vomiting, 156
  for pain management, 125, 365
Capacity
  consent and, 341
  definition, 737*b*
  delirium and, 327
  determination of, 828
  mental illness and, 510
Capsaicin, 125, 365
Cardiac cachexia, 140, 141*t*
Cardiology, outpatient palliative care and, 644–645
Cardiopulmonary resuscitation (CPR)
  discussions regarding, 69–71
  DNAR orders and, 827–828
  family presence during, 633
  imminent death decision regarding, 423
Cardiovascular implantable electronic devices (CIEDs), 424, 831–832
Caregivers. *See also* Families
  adolescents as, 786
  bereavement and, 391
  burdening of, 555
  clinical trials and, 666
  crisis in, 615–616
  delirium management and, 322–323
  family, for older adults, 486
  formal vs. informal, 486
  hope as perceived by, 381
  intensive care units and, 415, 625, 625*b*, 629–634, 629*b*, 631*t*
  meaning in illness and, 461
  occupational therapy training, 685
  for older adults, 486
  palliative surgery perspectives of, 660
  physical therapy training, 685
  stress and morbidity, correlation between, 48–49
  suffering of, 762
CARES (*Competencies and Recommendations for Educating Undergraduate Nursing Students*), 10, 692, 844, 850
Caritas Processes, 448, 449*t*
Catatonia, 321
Catheters, 202, 232–233
  indwelling pleural, 347
  urinary, 251
Catholicism, 479, 787
  mourning in, 391–392
Caucasians. *See* White populations
CBT. *See* Cognitive-behavioral therapy
CDC. *See* Centers for Disease Control and Prevention
Celecoxib, 119*t*
Center to Advance Palliative Care (CAPC), 581, 621, 693, 724
  community-based palliative care, 678
  hospital-based palliative care, 15–17, 20, 27
  National Consensus Project and, 811
  on quality improvement, 27, 27*t*
  State-by-State Report Card (2015), 13–15
  training and assistance from, 675
Centers for Disease Control and Prevention (CDC), 513, 646, 736
  children, death rates among, 736
  opioid prescription guidelines, 100, 104, 526, 647*b*
Centers for Medicare and Medicaid Innovations (CMMI), 610, 678
Centers for Medicare and Medicaid Services (CMS), 6, 251. *See also* Medicaid; Medicare
  on organ donation, 372, 546
  on pressure injuries, 254
  quality outcome measures, 575
  reimbursement, 814
Certification programs, 19–20, 813. *See also* Advanced Palliative Care Certification (TJC)
Certified Hospice and Palliative Care Administrator (CHPCA), 851
Certified Hospice and Palliative Licensed Nurse (CHPLN), 851
Certified Hospice and Palliative Nurse (CHPN), 851
Certified Hospice and Palliative Nursing Assistant (CHPNA), 851
Certified Hospice and Palliative Pediatric Nurse (CHPPN), 851
Certified in Perinatal Loss Care (CPLC), 851
Certified nurse practitioner (CNP), 810, 848
Certified nurse-midwife (CNM), 810, 848
Certified registered nurse anesthetist (CRNA), 810, 848
Change, contending with, 409
Chaplains, 433, 768. *See also* Spiritual care
  role on interdisciplinary teams, 90–91, 92*c*
Charcot, Jean-Martin, 254
Checklist of Nonverbal Pain Indicators (CNPI), 112*t*
Chemical coping syndromes, 524
Chemotherapy
  for bone metastasis, 353
  constipation resulting from, 187*b*
  diarrhea resulting from, 197, 197*b*
  dysphagia resulting from, 166
  fever and, 288
  nausea and vomiting from, 150
  neuropathy resulting from, 533
  nursing roles in, 667
  ocular toxicities resulting from, 275*t*
  for pain management, 125
  palliative, 665–667
CHEST Expert Cough Panel, 224
Chest multiple detector CT (MDCT), 348
Chest X-ray, 346
Child life specialists (CLSs), 94*c*
Children and adolescents, 473–474. *See also* Families; Family-centered palliative care; Pediatric end-of-life decision-making; Pediatric pain; Pediatric palliative care (PPC); Perinatal palliative care
  advance care planning, participation in, 743–745
  assessment for palliative care, 714
  bereavement by, 761–762, 767
  death as perceived by, 717*t*
  death rates, 736, 753
  health characteristics and utilization of care, 803
  parentally bereaved adolescents, 783–789
  responses to serious illness in family, 52, 52*b*, 783–789
  seizures in, 705
  untimely death of, 400
  visitation to ICU by, 633
Children's Health Insurance Program (CHIP), 712
  community-based palliative care and, 617
  hospice eligibility criteria, 801
Chinese medicine, traditional, 363, 364
Chiropractic, pain management and, 126
Chlorhexidine, 176
Chloride channel activators, 191
Chlorpromazine, 155
Cholestatic pruritus (CP), 287–288
Choline magnesium trisalicylate, 119*t*
Christianity, 787
Chronic breathlessness, 217–218
Chronic critical limb ischemia (CCLI), 266
Chronic illness. See also *specific diseases and conditions*
  aging and, 484
  in childhood, 714
  depression and anxiety, 310
  dysphagia resulting from, 167–168
  economic impact of, 849
  follow-up for patients with, 316–317
  hope and, 383
  trajectories of, 32
Chronic obstructive pulmonary disorder. *See* COPD
Chronic pain. *See also* Pain
  characteristics of, 99
  in children, 780–781
  complementary and integrative therapies for, 363–364
Chronic Respiratory Questionnaire, 220
CIM. *See* Complementary and integrative therapies
CINV, treatments for, 156, 157
"Circle of Caring" program, 463
Circulatory death, organ donation after (DCD), 549
Circulatory system, dying process and, 356
Cisapride, 154
City of Hope National Medical Center, 660, 813
Clergy, 433. *See also* Spiritual care
Clinical indicators, 585. *See also* Quality improvement
Clinical nurse specialist (CNS), 810, 848
Clinical pathways, for quality improvement, 582
Clinical Practice Guidelines for Quality Palliative Care (NCP), 5–11
  on advance care planning, 66, 827
  APRNs and, 811–812
  on bereavement, 758
  on communication, 62
  on culture, 470, 470*b*
  definitions and tenets, 6–7
  Domains of Care, 6*b*, 7–9, 7*b*, 16
  history of, 5*b*
  hospital-based palliative care, 15–17, 20–21
  implementation of, 9
  implications for nursing, 9–10
  on interdisciplinary teams, 90–92, 95–96
  on nursing education, 850–851
  on pediatric palliative care, 713
  on pulmonary palliative care, 552
  on quality improvement, 575
  research and, 857
  underserved populations and, 499
Clinical Saliva Scale for Motor Neuron Disease (CSS-MND), 177*b*
Clinical trials, 666, 741*b*
Clonidine, 779
CMS. *See* Centers for Medicare and Medicaid Services
Codeine, 120*t*, 121, 224
Cognition
  insomnia and, 332–333
  in older adults, 485
  speech language pathology and, 686
Cognitive deficits, 275

Cognitive distraction, for nausea and vomiting, 158*t*
Cognitive screening tools, 321–322, 321*t*
Cognitive-behavioral therapy (CBT), 315
  for bipolar disorders, 507
  for insomnia, 333–335
  for pain management, 126
  for personality disorders, 508
  for psychotic disorders, 505
Cognitively impaired patients, pain assessment in, 110–113, 110*t*, 111*b*, 112–113*b*
Collaboration
  communication and, 72–75
  delirium management, 327
  in palliative rehabilitation, 684
  in patient advocacy, 864
  in pediatric decision-making, 738–739
Colombia, 838
Colorado, 837
Colostomy, 251, 252*c*, 273, 339*c*
Coma, 627
Combat, culture of, 539–540
Comfort Care Orders, 67
Comfort Communication, 9
Comfort feeding, 608
COMFORT model for communication, 59–60
Communication, 55–75. *See also* Listening skills
  in advance care planning, 828*t*
  on advance care planning, 66–67, 66*b*, 691–692
  anxiety, role in, 60
  approaches, 63–65
  in assessment, 40–41
  bad news discussions, 68–69, 69*b*
  barriers to, 58–59
  cancer survivorship and, 535
  case studies, 55*c*, 61–63*c*, 68*c*
  COMFORT model, 59–60
  conflict resolution, 74–75, 74*b*
  core elements of, 60–63
  cultural considerations in, 62, 63*c*, 63*b*
  in decision-making, 738–739, 740*t*
  delirium and, 325–326
  with difficult-to-engage clients, 498*b*
  effective, 56, 56*b*, 59–60
  e-mail and web technology, 64
  on goals of care, 67–68, 68*b*, 71, 72*b*, 83
  impairment of, 298
  imparting information, 60–61
  information needs of patients and families, 56*b*, 59–60
  information-gathering, 61–62
  initiatives related to, 9
  interdisciplinary teams and, 23, 72–75
  intrateam, 23
  life-sustaining treatment discussions, 69–71
  medical language, translation to lay language, 58, 58*t*
  on medically administered hydration and nutrition, 71
  mentally ill patients and, 505–509, 511
  in nurse-patient relationships, 55–75, 57*t*
  older adults and, 485–486
  open-ended questions in, 61*b*
  optimizing, 298*b*
  overview, 55–56
  in palliative rehabilitation, 684
  parent-child, 784–786
  patient advocacy and, 863–864
  patient and family meetings, 64–65, 65*b*
  prognosis discussions, 69
  quality-of-life discussions, 70, 70*b*
  rehabilitation and, 684, 685
  role of nurse in, 56–59, 74
  scheduled meetings, 65
  on sexuality and intimacy, 341–342
  social media and, 64, 786, 791–797
  teach-back intervention, 316
  teamwork and collaboration in, 72–75
  telehealth technology and, 673–675
  on transition to palliative care or hospice, 71, 72*b*
  web technology and, 317
Community Health Accreditation Partners (CHAP), 621
Community Living Centers (CLCs), 607
Community-based palliative care, 615–622
  academic requirements for nurses in, 620–621
  background, 615
  case studies, 621–622*c*
  delivery models, 616–617
  effectiveness of, 616
  family caregivers, crisis among, 615–616
  future for nurses in, 621
  interdisciplinary teams in, 619, 620*t*
  for older adults, 483–488
  payment for, 617–619
  rules and regulations on nursing in, 620
  teams, 89, 95
  for underserved populations, 499–500
Comorbidities, 803
Compassion, 18, 449–450, 462, 879
Compassion fatigue, 634, 818–820, 818*t*, 834–835
The Compassionate Friends program, 396
Competencies and Recommendations for Educating Undergraduate Nursing Students (CARES), 10, 692, 844, 850
Competency, clinical, 812, 863, 878
Competency determination, 828
  delirium and, 327
  mental illness and, 510
Complementary and integrative therapies (CIM), 361–368. *See also* Mind-body therapies (MBTs)
  for anxiety, 315
  assessment and, 40
  case studies, 363*c*
  definition, 362
  for depression, 315
  for insomnia, 333
  malignant fungating wounds and, 269
  nausea and vomiting, 157
  for pain management, 126
  in pediatric palliative care, 701–702
  prevalence of use, 361–362
  resources for, 367
  spiritual care and, 448
  terminology, 362
Complete Decongestive Therapy (CDT), 245*c*, 246–247
Complex chronically ill children, 714
Complicated bereavement and grief, 50, 52*b*, 91, 394
  intensive care units and, 632
Compression garments, 245–246*c*, 247
Computed Tomography (CT) scanning, 346, 662
Concentrated ascites reinfusion therapy (CART), 202
"Concurrent Care for Children," 712–713
Confidence, 864
Confidentiality, 38
Conflict resolution, 74–75, 74*b*
Confusion, 319–327. *See also* Delirium
  dehydration and, 209, 210
  meaning and, 458–459
Confusion Assessment Method (CAM), 321
Confusion Assessment Method for ICU (CAM-ICU), 628
Congestive heart failure, 140. *See also* Heart failure
CONNECT trial, 691
Connecticut Coalition to Improve End-of-Life Care, 9
Conscious dying, 452–453
Conscious Dying Principles and Practices (CPDs), 452–453
Consensus Model for APRN regulation, 809–812, 814–815, 848
Consent
  in assisted dying, 840
  palliative sedation and, 357
  sexuality and, 341
Consequentialist theories, 824
Constipation, 186–192, 203
  assessment, 188, 188*t*
  case studies, 186*c*, 192*c*, 704*c*
  in children, 704
  definition, 186, 187*b*
  management, 188–192, 189*b*
  metabolic factors, 187
  neurologic factors, 187
  opioid-related, 186
  pathophysiology, 186–187
  pharmacological management, 189–192
  prevalence and impact, 186
  prevention of, 122
  structural factors, 187
Consult tools, 24–25*f*
Consultation process
  documentation of, 26
  initial consultation, 23–26
  inpatient consult teams, 89
Consultative Community-based palliative care programs, 616
Consumer Assessment of Healthcare Providers & Systems (CAHPS) Hospice Survey, 576
Continence. *See* Wound, ostomy, and continence (WOC) care
Continent fecal and urinary diversions, 272–273, 273*t*
Continued bonds, 399–400, 796
Continuing Care Retirement Communities (CCRCs), 606
Continuity of care, 27
Continuous deep sedation. *See* Palliative sedation
Continuous quality improvement. *See* Quality improvement (QI)
Control, hope and, 383
Controlled substances, 646–647
The Conversation Project, 9, 82, 574
COPD (chronic obstructive pulmonary disorder), 3–4, 103–104*c*
  anorexia and, 140, 141*t*
  case studies, 46*c*, 47–49*c*, 103–104*c*, 206*c*, 556–557*c*
  cough and, 224
  depression and anxiety, 309
  dyspnea and, 218, 220
  fatigue and, 132, 133, 133*b*
  palliative care, 552–557
  trajectory of, 32
Coping strategies, 35, 44–45, 65*b*

Coronary artery disease (CAD), homeless and poverty, association with, 492–493
Corticosteroids, 210, 350
  for nausea and vomiting, 156
  for pain management, 123, 124*t*
Cough, 217, 223–226
  assessment/measurement of, 224
  management, 224–225
  pathophysiology of, 224
Cough hypersensitivity syndrome (CHS), 224
Cough Specific Quality of Life Questionnaire, 224
Coyle, Nessa, 844
Coyne, Patrick, 844
CPAP (Continuous positive airway pressure), 224, 371, 373
CPR. *See* Cardiopulmonary resuscitation
CPT (current procedural terminology) codes, 693
Critical Access Hospitals (CAHs), 677
Critical Care Pain Observation Tool (CPOT), 112
Critical care settings. *See* Intensive care unit (ICU)
Critical-Care Pain Observation Tool (CPOT), 625
Cruzan, Nancy, 211
Cultural assessment, 472*b*, 473
Cultural competence, 37
  communication and, 62, 63*c*, 63*b*
  components of, 471–472
  in patient and family assessment, 37
Cultural considerations, 469–480. See also *specific racial and ethnic groups*
  assessment, 472*b*, 473
  in bereavement and mourning, 390–392
  case studies, 470–471*c*, 477*c*
  in communication, 477–478
  components of culture, 473–477
  definition of culture, 469
  diversity and, 469–470
  global setting for, 469
  guidelines for, 470, 470*b*
  hope and, 382–383
  interpreter services and, 37–38, 62
  in medical decision-making, 478–479
  in medically administered nutrition and hydration, 211–214
  in neonatal palliative care, 751–753
  nutrition and, 144
  palliative sedation and, 357
  in spiritual assessment, 443
  in United States, 469–470
  Web-based resources for healthcare issues, 472*b*
Curcuma longa (turmeric), 365
Current Opioid Misuse Measure (COMM), 526
Current procedural terminology (CPT) codes, 814
Current Procedural Terminology (CPT) codes, 617, 619*t*
Cyclizine, 155
Cyclothymia, 505–506

Dalai Lama, 29
Dark night of the soul, 459
Day-to-day living, 409–410
Death and dying. *See also* Active dying; Assisted dying; Planning for actual death
  active dying, assessment during, 49–53, 50*t*, 51*t*
  adolescent exposures to, 787
  children's perceptions of, 762
  communication regarding transition to, 72
  conscious dying, 452–453
  continued bonds and, 399–400, 796
  cultural considerations in, 479–480
  dying process, 356
  estimated time until, 357
  forewarning of, 393
  funeral plan assessments, 53*b*
  good death, 359, 398
  hastening, 830–831
  at home, 615
  at hospitals, 615
  in intensive care units, 624, 627
  leading causes of, 484*b*
  palliative sedation and, 357
  in pediatric care, 722–724, 749, 801
  physical symptoms, 50*t*
  planning for, 420–430
  poor populations and, 493–495
  preparing for, 410
  pronouncement of death, 18, 427
  sedation for refractory symptoms, 356–359
  untimely death, 400
  ventilator withdrawal and, 374
  veterans and, 540
Death Cafes, 693
Death education, 634
Death rattle, 225–226. *See also* Terminal secretions
  assessment of, 225
  management, 225–226
  ventilator withdrawal and, 631
Debridement, 258*b*, 259*t*
Decision-making. *See also* Pediatric end-of-life decision-making; Surrogate decision-makers; Withdrawal of life-sustaining treatments
  autonomous, 738
  definition, 737*b*
  influences on, 740–741
  medical team recommendations in, 739–740
  in pediatric oncology, 736–747
  shared, 738–739
Decision-making and goals of care, palliative chemotherapy, 665–666
Decompression surgery, 350
Deep sedation, continuous. *See* Palliative sedation
Deep South Cancer Navigation Network, 676
Defibrillators, 424
Dehydration, 208, 209–210, 214, 225. *See also* Hydration; Medically administered nutrition and hydration
  terminal, 424
Delirium, 319–327
  assessment, 321–322
  case studies, 324*c*
  collaborative care, 327
  decision tree, 323*f*
  dehydration and, 209, 210
  differential diagnosis, 320–321
  epidemiology and prognosis, 319–320
  ethical considerations, 327
  in intensive care unit, 628
  legal considerations, 327
  management, 322–327
  nonpharmacological management, 325–327
  pathophysiology and etiology, 320
  pharmacological management, 324–325
delta-9-tetrahydrocannabinol (THC), 365
Dementia. *See also* Alzheimer's disease
  case studies, 165*c*, 429–430*c*
  delirium vs., 320–321
  dysphagia resulting from, 167
  pain assessment and, 110–111
  trajectory of, 32
Deming Wheel, 575
Demoralization, 312
Denosumab, 352
Deontological theories, 824
Dependent personality disorder, 508
Depression, 309–317
  acupuncture for, 366
  assessment and screening considerations, 269, 310–311
  assessment of, 47*t*
  bereavement and, 391, 393
  bipolar disorders and, 506–507
  in cancer survivors, 533
  in caregivers, 632
  diagnosis, 311–312
  differential diagnosis, 312
  differentiation from grief, 35*t*, 36, 312
  DSM criteria for, 36, 311
  fatigue and, 134
  heart failure and, 566
  integrative therapies, 315
  pharmacological management, 313–314
  prevalence, 309, 310*t*
  psychotherapeutic interventions for, 314–315
  signs and symptoms, 47, 47*t*
  treatment, 312
Depression Cancer Consensus Group, 310
Developmental stages, 473–474
  adolescence, 783–784
  perceptions of death and, 717*t*
Dexmedetomidine, 125, 627
Dextromethorphan, 224
Diagnostic and Statistical Manual of Mental Disorders (5th ed.; *DSM-5*)
  delirium criteria, 319
  depression criteria, 36, 311
  grief, 393, 395
  personality disorders, 508
  substance use disorders, 522
Diagnostic assessment, 40–46
  physical component, 41–44
  psychosocial component, 44–45
  spiritual component, 45–46
Diagnostic paracentesis, 201
Dialectical behavioral therapy (DBT), 508
Dialysis, 352
  discontinuation of, 424–425
  poor populations and, 493
Diarrhea, 186, 196–200, 203
  assessment, 197–198
  case studies, 196*c*, 200*c*
  definition, 196
  diagnostic studies, 198
  infection-related, 196–197
  management, 198–200
  nursing interventions for, 198–199
  pathophysiology and risk factors, 196
  pharmacological management, 199–200
  physical examination, 198
  prevalence and impact, 196
  prevention, 198
Diazepam, 358
Diet. *See* Nutrition
Dignity, 357, 478, 839–840

- Dignity laws, 830, 837, 840
- Dignity therapy, 439, 463
- Diphenhydramine, 155
- Disability
  - intellectual, children with, 803
  - rehabilitation and, 684–686
- Disability status, 477
- Disenfranchised grief, 394–395
- Disorientation, 326
- Distress, emotional, 533
- District of Columbia, 837
- Diuretics, 201
- Diversity, in U.S., 469–470, 483
- DNAR. *See* Do Not Attempt Resuscitation (DNAR) orders
- DNR. *See* Do Not Resuscitate orders
- Do Not Attempt Resuscitation (DNAR) orders, 826–828
- Do Not Intubate orders (DNI), 70
- Do Not Resuscitate orders (DNR), 67, 70–71, 499, 692
  - definition, 737*b*
  - delirium and, 324*c*
  - in electronic medical records (EMR), 26
  - intensive care units and, 630
  - terminology change to DNAR, 827
- Doctorate of Nursing Practice, 811
- Documentation
  - of advance directives, 39
  - of consultations, 26
  - of spiritual assessments, 443–444
- Dolasetron, 155
- Domperidone, 154
- Donate Life America, 547
- Donation after circulatory death (DCD), 549
- Dopamine receptor antagonists, 155
- Double effect, principle of, 357, 627
- Drainage control, 260*t*
- Dressings, 255, 258, 260*t*
- Drinking, 208, 424. *See also* Dehydration; Hydration; Medically administered nutrition and hydration (MAHN)
  - voluntary refusal of, 834, 841
- Dronabinol, 156
- Droperidol, 155
- Drugs. *See* Medications
- Drug-seeking behaviors, 524. *See also* Substance use disorders (SUD)
- Dry mouth. *See* Xerostomia
- *DSM-5. See* Diagnostic and Statistical Manual of Mental Disorders
- Duchenne muscular dystrophy (DMD), 167, 304–306
- Dufault, Karin, 379
- Durable power of attorney for healthcare (DPOA), 38–39, 66, 82, 327, 422, 691–692, 826. *See also* Surrogate decision-makers
- Dying. *See* Death and dying
- *Dying in America* (NAM), 5, 9, 27, 80, 573, 620, 691, 810, 812
- Dysgeusia, 163, 179–182
- Dysphagia, 163–173, 182
  - assessment of, 168, 169*b*
  - case studies, 163*c*, 165*c*
  - definition, 163
  - etiology of, 165–168
  - management, 169–173
  - medically administered hydration and, 172, 207–208
  - physiology and pathophysiology of, 163–165, 164*f*
  - speech language pathologists and, 685, 686
  - speech-language pathologists, role in, 168–169
- Dyspnea, 217–223, 226
  - assessment of, 629
  - behavioral strategies, 222–223, 223*t*
  - case studies, 218*c*, 703*c*
  - in children, 702–703, 719
  - crisis, 217
  - definition, 217
  - empathy exercise, 553*b*
  - heart failure and, 218, 565–566
  - importance of, 553
  - in intensive care unit, 629
  - management, 220–222, 629
  - measurement of, 220, 221*t*
  - mechanical interventions, 222, 372
  - nonpharmacological management, 222–223, 223*t*
  - occupational and physical therapy for, 686–687
  - oxygen therapy for, 374
  - pathophysiology of, 218–219
  - patient experience, 218
  - pharmacological management, 222
  - pleural effusions and, 346
  - speech language pathology and, 686–687
  - terminology, 217
- Dyspnea Management Questionnaire, 220
- Dyspnea-12 (D-12), 220

- Ecograms, spiritual, 439
- Ecomaps, spiritual, 439
- Economic outcomes, in hospital-based palliative care, 28–29
- ED. *See* Emergency department
- Edema, 350. *See also* Lymphedema
  - definition, 240
  - heart failure and, 566
  - lymphedema, compared to, 239*t*, 248, 249
  - treatment, 246
- Edmonton Symptom Assessment System (ESAS), 142, 220, 310
- Edmonton Symptom Assessment System-r (ESAS-r), 109–110
- Education. *See* Nursing education; Patient education
- Educational Development Center (EDC), 724
- Elderly patients. *See* Older adults
- Electronic health records (EHR)
  - patient and family assessment and, 38–40
  - spiritual assessment and, 444
- Electronic medical records (EMRs)
  - advance directives, 26
  - consultations documented on, 26
- Elephantiasis, 239
- ELNEC (End-of-Life Nursing Education Consortium), 511, 692
  - community-based nursing curriculum, 620
  - continuing education program, 19, 813, 845
  - curriculum development and implementation, 845–848
  - ELNEC-International, 870
  - ELNEC-Undergraduate, 847–848
  - emergency department training, 655
  - international programs, 851
  - NCP *Clinical Practice Guidelines* and, 9, 10
  - neonatal/PPC curriculum, 755
  - outpatient palliative care and, 648
  - pediatric palliative care training, 724
  - primary palliative care, 17
  - train the trainer initiatives, 845
- E-mail communication, 64. *See also* Internet
- Embolization, 353
- Emergency department (ED), 652–658
  - barriers and challenges to palliative care in, 653–656
  - case studies, 653*c*, 656*c*, 657*c*
  - current gaps and next steps, 657–658
  - facilitators to palliative care in, 656–657
  - goals of care in, 653–654
  - incidence, prevalence and causes, 652–653
  - palliative care in, 652–658
- Emetic pathways, 151*f*. *See also* Nausea and vomiting
- Emotional coping, HIV and, 516–517
- Emotional issues. *See also* Bereavement; Grief; Meaning in illness; Mourning
  - child's death and, 761–762
  - distress, in children, 705–706
  - insomnia and, 332–333
  - positive emotions, 821–822
- Emotional labor, 818
- Empathy, 421, 450
- Empowerment, 316. *See also* Self-management techniques
- End-of-life (EOL) care. *See also* Active dying; Death and dying; Pain management; Planning for actual death; Withdrawal of life-sustaining treatments
  - costs of, 573–574
  - definitions, 251, 573
  - ethical considerations, 826–828
  - gaps in, 855
  - in intensive care units, 624
  - quality improvement, 573–586
  - refractory symptom management, 126–127
- End-of-Life Nursing Education Consortium. *See* ELNEC
- Endotracheal intubation, 371, 373
- End-stage renal disease (ESRD). *See also* Dialysis
  - anorexia and, 140, 141*t*
  - depression and anxiety, 310
  - fatigue and, 132, 133, 133*b*
  - poor populations and, 493
- End-stage skin failure, 254
- Enemas, 190–191
- Energy therapies, 361, 366
- Engagement, 819
- Enteral nutrition and hydration, 144, 207, 209
- EPEC (Education in Palliative and End-of-Life Care), 9, 17, 19
- Epidural, 122
- Erectile dysfunction, 339*c*
- Erythromycin, 155
- ESRD. *See* End-stage renal disease
- Eszopiclone (Lunesta), 335
- Ethic of care, 825
- Ethical considerations, 824–835
  - in advance care planning, 826–828
  - case studies, 825–826*c*
  - definition, 824
  - delirium and, 327
  - in goal-setting, 826–828
  - hastening death, 830–831
  - interdisciplinary teams and, 94*c*
  - in medically administered nutrition and hydration, 211
  - moral reasoning and, 824–825
  - nursing issues, 834–835
  - principlist approach to, 824–825
  - social media use and, 797

- Ethnicity, 473, 479. *See also* Cultural considerations; *specific racial and ethnic groups*
  - health disparities and, 493
- Ethos of palliative nursing, 877–880
  - beauty, 879
  - case studies, 877–878*c*
  - Imagination, 878–879
  - presence, 879–880
  - space, 879
  - trustworthiness, 878
- Euro-American cultures, hope and, 382–383
- European Association for Palliative Care (EAPC), 838
  - on fatigue, 135
- European Society for Intensive Care Medicine, 833
- Euthanasia, 830–831, 837. *See also* Assisted dying; Physician-aid-in-dying (PAD); Physician-assisted suicide
- Evaluation and management (E&M) CPT codes, 814
- Exercise and physical activity
  - in complementary and integrative therapies, 364
  - for dysphagia, 169
  - for insomnia, 333
  - lymphedema and, 244, 248–249
  - for mood and sleep, 365
  - for nausea and vomiting, 158*t*
- Existential issues, insomnia and, 332–333
- Existential suffering, 357–358, 705–706, 840
- Experiential process of hope, 386
- External consultation teams, in nursing homes, 609
- Extubation, 373, 630, 631*t*

- Facebook, 786, 791, 792
  - illness blogs on, 793–794
- Faces Pain Scale-Revised (FPS-R), 107, 107*f*, 109*t*, 773
- FACIT-Sp (Functional Assessment of Chronic Illness Therapy-Spiritual Well-being), 535
- FACT spiritual assessment model, 438
- Fallen Comrade ceremony, 542–543
- Falls, 485*b*
- FAMCARE scale, 583
- Families. *See also* Caregivers; Children and adolescents; Family-centered palliative care; Patient and family assessment; Pediatric palliative care (PPC); Siblings
  - assessment of, 763
  - bereavement, 391, 400–401, 758–770
    - complicated, risk factors for, 52, 52*b*
  - burdening of, 555
  - clinical trials and, 666
  - delirium management and, 322–323
  - emergency departments and, 655
  - grief and grief interventions for, 400–401, 758–770
  - hope as perceived by, 381
  - intensive care units and, 415, 625, 625*b*, 629–634, 629*b*, 631*t*
  - of LGBTQ patients, 342
  - meetings with, 26, 64–65, 65*b*, 422, 422–423*t*
  - mentally ill patients and, 511
  - organ donation discussions, 547–548
  - pediatric assessment and, 699
  - satisfaction with quality of care, 582–586
  - social media communication and, 795
  - therapy for, 315
  - unpaid caregiving by, 615–616
- Family Assessment of Treatment at the End-of-Life (FATE) tool, 582
- Family-centered palliative care, 9, 29, 405–417, 751*b*
  - advance care planning and, 415–417
  - caregiver assessment, 412–414
  - caregiver support, 414–415
  - caregivers' quality of life, 412
  - in intensive care units, 632–634
  - pediatric, 699
  - principles of, 709–712*b*
  - recommendations on, 691
  - transition of fading away, 406–412
- Fatigue, 132–139
  - assessment of, 135, 135*b*
  - cancer survivorship and, 532–533
  - cancer-related (CRF), 132–138, 133*b*
  - definition, 132–133
  - dyspnea and, 219
  - factors influencing, 134–135, 134*b*
  - heart failure and, 133*b*, 566
  - herbal interventions, 136
  - insomnia and, 330
  - management and treatment of, 135–138, 137*t*
  - nonpharmacological management, 136–138
  - occupational and physical therapy for, 686
  - pathophysiology of, 134
  - pharmacological interventions, 136
  - prevalence and populations at risk, 133, 133*b*
- Fatigue Observation Checklist, 135
- Fatigue Practice Guidelines (NCCN), 133
- Fatigue Scale, 135
- FDA (Food and Drug Administration), 133*b*, 136, 144, 154–156, 166, 173, 191, 199, 306, 334–335, 351–352, 366–367, 508
- Fear of Disease Progression Scale, 311
- Fecal incontinence, 279–280
- Federal policy, 801
- Feeding tubes, 144, 163, 167, 279
- Fee-for-service (FFS) model, 617–619, 690
- Feet, lymphedema and, 248
- Feminist ethics, 825
- Fentanyl, 120–121, 120*t*, 196
- Ferrell, Betty, 844
- Fertility, 341
- Fetal death, 753–755
- Fever, 288–289
  - case studies, 289*c*
  - imminent death and, 423
- FICA spiritual assessment model, 435, 436*t*, 444, 535
- Fidelity, 357
- Final common pathway, 219
- Financial literacy, 476
- Fistulas, 277–279
  - case studies, 272*c*
- Five Wishes document, 826–827
- FLACC assessment, 112*t*
- Florida, hospice policy, 801
- Fluid deficit disorders, 208
- Fluid retention, 209–210
- FOCUS-PDSA model, 577–579, 588–590*f*
- Food. *See also* Medically administered nutrition and hydration; Nutrition
  - care and, 206
  - comfort feeding, 608
  - cultural considerations, 479
  - oral feeding, 172*b*, 608
  - in pediatric palliative care, 704–705
  - texture and consistency, dysphagia and, 170–171, 172*b*
  - voluntary refusal of, 834, 841
- Forewarning of death, 393
- Forgiveness, 450
- Fosaprepitant, 156
- Four Seasons Compassion for Life, Western North Carolina, 678
- Fractures, pathological, 352–353
- Frailty, 167–168
- Frankl, Viktor, 36, 463
- Free-standing palliative care programs, 617
- Functional Assessment, 43–44*b*
- Functional Assessment of Anorexia/ Cachexia Therapy (FAACT), 143
- Functional Assessment of Chronic Illness Therapy-Dyspnea (FACIT-Dyspnea), 220
- Functional decline, 485
- Functional medicine, 362
- Funding sources, for research, 857
- Funerals
  - assessment of plans for, 53*b*
  - mourning and, 391–392
  - rituals and, 768
- Futility, of interventions, 833–834
- *The Future of Nursing: Leading Change, Advancing Health* (NAM), 10, 810, 849

- Gabapentin, 779
- Gangrene, 266
- GAP index, 556
- Gastric outlet obstruction (GOO), 663
- Gastroesophageal reflux disease (GERD), 224
- Gastrointestinal system
  - dying process and, 356
  - mind-body approaches for, 366–367
  - natural products for, 367
  - pediatric palliative care and, 703–705, 719
- Gastrojejunostomy (G-J) tubes, 207, 703
- Gay populations. *See* LGBTQIA (lesbian, gay, bisexual, transgender, queer/questioning, intersex, and asexual) populations
- Geisinger Medical Center, 553, 555–556
- Gender
  - bereavement and, 390–391, 400, 784
  - cultural considerations, 474–475, 480
  - depression and anxiety and, 309–310
  - moral reasoning and, 825
- Gender identity, 475, 475*b*, 499*c*
- General adaptation syndrome (GAS), 817–818
- Generalized Anxiety Disorder 7 (GAD-7), 310–311
- Generalized hope, 379
- Generosity, 450
- Genetic testing, 41
- Genograms, 38, 39*f*
  - spiritual, 439
- Geriatric palliative care, 483–488. *See also* Older adults
- Geriatric syndromes, 485
- Gerontology, outpatient palliative care and, 646
- Ghrelin, 141, 145
- Ginger, 158, 367
- Global Atlas of Palliative Care, 868, 869*f*
- Global Burden of Disease study, 503
- Global meaning, 37
- Global Observatory on Donation and Transplantation (GODT), 545
- Global palliative care, 868–875
  - barriers and challenges, 868–874
  - essential medicines for, 871*t*
  - evidence-based practices in, 871–872
  - in low- or middle-income countries, 868–875
  - nursing education and, 851
  - nursing role in, 875

  opioid distribution and, 872*f*
  organizations, 873–874*t*
  palliative care initiatives, global and regional, 868–869, 874–875
  rural, 673
Glucocorticoids, 144
Goals of care
  communication and, 67–68, 68*b*, 71, 72*b*, 83
  delirium and, 326–327
  in emergency department (ED), 653–654
  evolving choices in, 421–422
  in intensive care units (ICU), 624–625, 625*b*
  medically administered nutrition and hydration (MAHN) and, 214
  palliative surgery, 660, 661*f*
  in pediatric end-of-life decision-making, 727–734
  pediatric palliative care (PPC), 701, 727–734
  for substance use disorders (SUD), 527
  value-based care and, 733
God, absence of, 459
Gold Star Mother/Gold Star Wives, 541*b*
Graft-versus-host disease (GVHD), 48
Grandparents, grief of, 761, 766. *See also* Families
Granisetron, 155
Gratitude, 822
Great Britain, 6, 676
Grief. *See also* Bereavement; Loss; Mourning
  anticipatory, 44, 341, 393–394
  assessment of, 397*b*, 762
  complicated, 394
  definition, 390, 759
  differentiation from depression, 35*t*, 36
  disenfranchised, 394–395, 784
  donation community as source of support, 549
  end of, 399
  expressions of, 395–396
  family dynamics in, 400
  nature of, 392–393
  of older adults, 485
  parental, 400, 755, 758–770
  preparatory, 312
  as process, 758
  types of, 393–395, 759–760*t*
  uncomplicated, 394
  unresolved, 395
Grief distress, 762
Group homes, 606
Group therapy, 687
Guanylate cyclase-*c* receptor agonists, 191
Guided imagery, 364, 367
  for pain management, 126
Guided Participation Theory, 764–766
Guidelines, 6, 10, 90, 811–812. See also *Clinical Practice Guidelines for Quality Palliative Care* (NCP)
  for value-based palliative care, 691–693

H_2 blockers, 195
HAART (highly active antiretroviral therapy), 142
Haloperidol, 155, 358, 628
Hand-feeding, 608
Haptics, 56
Harvard Medical School Center for Palliative Care, 19
Hastening death, 830–831. *See also* Assisted dying
HBPC. *See* Hospital-based palliative care
HCPOA (healthcare power of attorney). *See* Durable power of attorney for healthcare
Head and neck cancer, 165, 249*b*
Headaches, 297–298
Healing Touch (HT), 366
HEALS, 435
Health Care Financing Administration (HCFA). *See* Centers for Medicare and Medicaid Services (CMS)
Health disparities, 493–495, 500
Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, 674
Health insurance, 39. *See also* Children's Health Insurance Program (CHIP); Medicaid; Medicare
  pain medication coverage, 106
Health Insurance Portability and Accountability Act of 1996 (HIPAA), 38, 511, 547
Health literacy, 316, 476
Health numeracy, 476
Health policy, 29
  access and, 800–801
  social media and, 804
Healthcare agent, 82
Healthcare power of attorney. *See* Durable power of attorney for healthcare
Healthcare professionals
  education and training, 848–849
  grief and, 762–763, 767–768
  interactions with adolescents, 788
  in rural areas, 676–677
  satisfaction with quality of care, 582–586
  social media and, 796–797
  support for, 634 (*See also* Self-care)
Healthcare proxy, 82, 826
  decision-making by, 828–829
Healthcare Reform Act (1992), 574
Healthcare Reform Act (2006), 801
Healthcare representative, 82
Heart failure, 559–568
  advance care planning and, 567
  assessment, 562
  cachexia and, 566
  case studies, 493*c*, 568*c*
  children with, 803
  classification systems, 560, 561*t*
  congestive heart failure, 140
  definition, 559
  depression and, 310, 566
  disease trajectory, 560
  dyspnea and, 218, 565–566
  edema and, 566
  ethical considerations in, 832
  fatigue and, 133*b*, 566
  lifestyle recommendations, 565
  mechanical circulatory support, 565
  pain and, 566
  pharmacological treatment, 563–565
  prognosis, 560–561
Heart transplantations, 565
Heat, pain management and, 126
Hematuria, 235
Hemoptysis, 347–348, 349*t*
Hemorrhagic cystitis, 234–235
Herbal medicine, 126. *See also* Complementary and integrative therapies (CIM)
  for insomnia, 335
  for nausea and vomiting, 158
Heroin, 522
Heteronormativity, 341–342
Hiccups, 173–175, 182
  assessment of, 174
  case studies, 173*c*
  definition, 173
  management, 174–175, 174*b*
  nursing interventions for, 175
  pathophysiology of, 173–174
  prevalence and impact of, 173
Hierarchy of needs, 36, 46
HIFU, 353
Highly active antiretroviral therapy (HAART), 142
Hill-Burton Act, 607
Hinds, Nancy, 844
Hinduism, 479
HIPAA. *See* Health Insurance Portability and Accountability Act of 1996 (HIPAA)
Hippocratic Oath, 839
Hispanic populations, 469, 470*t*
  children in hospice care, 803
  hope among, 382
  pain assessment and, 479
  poverty among, 491
History and physical examination (H&P), 39
Histrionic personality disorder, 508
HIV/AIDS, 513–519
  advance care planning and, 517
  anorexia and, 140, 141*t*, 142, 144
  antiretroviral therapy for, 142
  case studies, 517–519*c*
  diarrhea and, 196–197
  disenfranchised grief and, 394
  fatigue and, 132, 133, 133*b*
  long-term survivors, coping strategies of, 515–517
  multimorbidity and aging, 515
  pain management in, 514
  palliative care, need for, 514–515
  pruritus and, 288
  wasting syndrome, 140, 141*t*
HIV-associated neurocognitive disorders (HAND), 514
Holistic medicine, 362. *See also* Complementary and integrative therapies (CIM)
Holistic nursing, 448
Home care. *See* Community-based palliative care
Home care nursing, ventilator withdrawal, 373–374
Home healthcare agencies (HHC), 616–617
Home hospice care, antiemetic selection in, 157
Home-based palliative care, 3–4
  family caregivers and, 414
Homeless populations, 476–477. *See also* Poor populations
  assessment, 497–498
  case studies, 493*c*
  death, causes of, 492–493
  definition and prevalence of, 491–492
  health problems, 492
  therapeutic relationships with, 497–498
Honesty, 878. *See also* Truth-telling
Hootsuite (social media application), 791
Hope, 379–390
  adaptation to illness, influence on, 380
  assessment of, 384–385
  in bereavement counseling, 397
  case studies, 381*c*, 382*c*
  in children and parents, 380
  definitions and dimensions of, 379–380
  experiential process interventions, 386
  family caregivers' perspective on, 381
  generalized, 379

Hope (*Cont.*)
  in hospice care, 398
  models for maintaining, 383, 385–387, 385*b*
  multicultural views of, 382–383
  nurses' self-knowledge and, 387
  nursing interventions at end of life and, 385–387, 385*b*
  in older adults, 381
  particularized, 379
  rational thought process interventions, 387
  reframing, 463
  relational process interventions, 386–387
  spiritual process interventions, 386
  in terminally ill patients, 381–382, 382*b*
  unrealistic, 383–384
HOPE spiritual assessment model, 436*t*
Hopelessness, 312
Hopi Indian mourners, 392
Hospice and Palliative Credentialing Center (HPCC), 8, 851
Hospice and Palliative Nurses Association (HPNA), 5*b*, 9, 10, 20, 22
  advocacy information online, 804
  on definition of palliative care, 285
  on dyspnea, 220
  educational programs and resources, 10, 620–621, 845, 851
  establishment of, 724
  guidelines on hastening death, 830
  National Consensus Project and, 811
  online resources, 675
  palliative care research and, 856
  on pediatric decision-making, 737, 746
  on quality standards, 577, 619
  Scope and Standards, 812
  on spiritual care, 433
Hospice and Palliative Nurses Foundation (HPNF), 851
Hospice care, 4. *See also* Pediatric hospice
  community-based palliative care by, 617, 802
  complementary and integrative therapies, 361
  definition, 709
  distribution of illnesses in, 33*t*
  evolution of, 709
  hope in, 398
  inpatient, 18
  interdisciplinary teams, 89, 95
  in nursing homes, 609
  transition to, 71, 72*b*
Hospice Pressure Ulcer Risk Assessment Scale, 260
Hospice/palliative healthcare team (HPHT), 788–789. *See also* Interdisciplinary teams
Hospital Anxiety Depression Scale (HADS), 309–310
Hospital-based palliative care (HBPC), 13–29
  advance care planning in, 39
  barriers to, 16
  bereavement programs, 768
  case studies, 13*c*
  consultation process in, 23–26
  day-to-day operations, 26
  documentation, 26
  economic issues in, 28–29
  family caregivers and, 414–415
  future directions of, 29
  growth of, 16, 28*f*
  history of, 13–15, 14*b*
  inpatient hospice and palliative care units, 18
  interdisciplinary education, 18–20
  interdisciplinary teams in (IDT), 17–18, 22–27
  models of, 17–18
  outcomes, measurement of, 27, 27*t*
  outpatient/ambulatory care clinics, 53*b*
  percent of hospitals with, 28*f*
  professional societies, contributions to, 21–22
  program development, 22
  program models for, 22–27
  public policy, influence on institutional, state and national, 29
  quality improvement and research in, 27, 27*t*
  quality of care issues, 16
  regional availability of, 677
  standards development for, 16, 20–21
  transitions of care and continuity in, 27
Housing First policy, 499
HPNA. *See* Hospice and Palliative Nurses Association
Human Caring Science, 448
Humanbecoming School of Thought, 449
Humility, 864
Hunger concerns, 208, 214, 829. *See also* Nutrition
Hunters Hill Marie Curie Center Risk Assessment tool, 260
Huntington's disease (HD), 301–303
Hydration, 208–211. *See also* Dehydration; Medically administered nutrition and hydration
  hypercalcemia and, 351
Hydrocodone, 120*t*, 121–122
Hydromorphone, 120*t*, 121
Hydroxyzine, 155
Hypercalcemia, 187, 350–352
Hyperglycemia, 187
Hyperthermic intraperitoneal chemotherapy (HIPEC), 202
Hypnosis, 159, 366–367, 627
Hypoalbuminemia, 200
Hypodermoclysis, 209
Hypothyrodisim, 187

Iatrogenic causes of diarrhea, 197
Ibuprofen, 118, 119*t*
ICD 10 codes, 617, 618*t*, 814
ICU. *See* Intensive care unit
Idiopathic pulmonary fibrosis (IPF), 218, 218*c*
Ileostomy, 251
Illicit drug use, 522. *See also* Substance use disorders (SUD)
Imagery rehearsal. *See* Guided imagery
Immigration status, 477
Implantable cardioverter-defibrillators (ICDs), 565
Improving Medicare Post-Acute Care Transformation Act (IMPACT Act), 576–577
Improving Palliative Care through Teamwork (IMPACTT), 610
Improving Palliative Care-Emergency Medicine (IPAL-EM), 656
Incompetency, defined, 828
Inconsistent telling, 785
Incontinence, 251. *See also* Urinary incontinence (UI)
  case studies, 233*c*
  urinary, 233, 235
Incontinence-associated dermatitis (IAD), 279–280
Incontinent fecal and urinary diversions, 272–273, 273*t*
Independence at Home (IAH) Demonstration, 617
Independent living facilities (ILFs), 616
Individualized, family-centered developmental care (IFCDC). *See* Family-centered palliative care
Indomethacin, 119*t*
Indwelling pleural catheters, 347
Infant mortality rates, 749
Infants, 473–474. *See also* Children and adolescents; Perinatal palliative care
  in neonatal intensive care unit (NICU), 749–756
Infection control, for wounds, 256
Informed consent, 840
Infrared perometry, 243, 244*f*
Initiative for Pediatric Palliative Care (IPPC), 724
Insomnia, 330–335
  assessment, 330–332
  case studies, 330–331*c*
  definition, 330
  diagnosis, 330
  factors related to, 331–333
  management, 333–335
  nonpharmacological management, 333, 334*t*
  nursing interventions for, 332–333
  pathophysiology, 331
  pharmacological interventions, 333–335
  prevalence and impact, 330
Instagram, 792
Institute for Healthcare Improvement (IHI), 82, 574
Institute of Medicine (IOM). *See* National Academy of Medicine (NAM)
Institutional policy, 29
Institutional Review Board (IRB) proposals, 857
Instrumental activities of daily living (IADLs), 685
Insurance. *See* Children's Health Insurance Program (CHIP); Health insurance; Medicaid; Medicare
Integrative health, definition, 362
Integrative Model of Curing and Healing, 758, 759*f*
Integrative therapies. *See* Complementary and integrative therapies
Intellectual disability, 803
Intensity scales, in pain assessment, 107–110, 109*t*
Intensive Care Delirium Screening Checklist (ICDSC), 628
Intensive care unit (ICU), 624–636
  access for families of patients, 632–633
  advance care planning and, 79, 84*c*, 85
  anxiety, agitation, and sedation in, 627–628
  caregiving activities, family involvement in, 633
  case studies, 634–636*c*
  deaths in, 624, 627
  distressing symptoms in, 629
  dyspnea assessment and management in, 629
  families of patients in, 415, 625, 625*b*, 629–633, 629*b*, 631*t*
  goals of care in, 624–625, 625*b*
  health professionals, support for, 634
  information and support in, 633
  limitations of end-of-life care in, 624
  neonatal (NICU), 749–756
  pain assessment and management in, 625–627
  palliative care planning in, 624–625
  spiritual assessment in, 444
  ventilators and, 372, 630–631, 632*b*

  withholding and withdrawal of life-sustaining therapies, 629–631, 632*t*
Intent, defined, 357
Intentionality, 449
Interdisciplinary teams (IDT), 89–96
  ambulatory care, 89, 95
  building, 95–96
  case studies, 92–94*c*
  communication in, 23, 72–75
  in community-based palliative care, 89, 95, 619, 620*t*
  end-of-life decision-making and, 746–747
  hospice, 89, 95
  hospital-based, 15, 17–18, 22–27, 89
  inpatient consult teams, 89, 94–95
  interactions with adolescents, 788–789
  nursing homes, 607–608
  in outpatient palliative care, 89
  payment for, 617–619
  in pediatric palliative care, 716–717
  sustaining, 96
  team members, roles of, 90–94*c*
International Association for the Study of Pain (IASP), 98
International Classification of Diseases (ICD 10) codes, 617, 618*t*, 814
International Dysphagia Diet Standardisation Initiative, 171
International palliative care. *See* Global palliative care
International Skin Tear Advisory Panel (ISTAP) Skin Tear classification system, 262, 266*f*
Internet. *See also* Web technology
  communication and, 64, 317
  palliative care resources, 675–676
  social media as communication tool, 64, 786, 791–797
Interpreter services, for patients and families, 37–38, 62
Interprofessional palliative care education (IPE), 850
Intersex populations. *See* LGBTQIA (lesbian, gay, bisexual, transgender, queer/questioning, intersex, and asexual) populations
Interstitial lung disease (ILD), 554–556
Interventional therapies, 125–126
Interventions to Reduce Acute Care Transfers (INTERACT) tools, 610
Intimacy, 337–342
  definition, 337
Intracranial tumors, 304, 305*t*
Intraspinal dosing, 122
Intrateam communications, 23
Intrauterine fetal demise (IUFD), 753–755
Intravenous inotrope therapy, 565
Inventory of Complicated Grief, 394
Islam, 479, 737
Itching. *See* Pruritus

The Joint Commission (TJC), 21
  Advanced Palliative Care Certification, 5*b*, 9, 21, 621, 811–812, 844
  Community-Based Palliative Care Certification, 9
  on cultural competence, 37
  on pain management, 100
  quality improvement, 580–581, 585
  on spirituality, 433
  standards for palliative care, 17
Joint integrity, 685
Journal of Hospice and Palliative Nursing (JHPN), 851
Journal of Palliative Medicine (JPM), 851
Judaism, 392, 480
Justice, 839
Juveniles. *See* Children and adolescents

Karnofsky Performance Scale, 309
Kennedy, Edward (Ted), 13, 29
Ketamine, 124, 126*b*, 222, 779
Ketorolac, 119*t*
Key performance indicators (KPIs), 585
Kidney disease. *See* End-stage renal disease (ESRD)
Kidney transplants, 493
Kindness, 29, 450
KTUs (Kennedy terminal ulcers), 254
Kübler-Ross, Elizabeth, 393

Labor and delivery (L&D), 749–750, 753–755
LACE regulation, 809
Lactobacillus, 192
Language
  cultural considerations, 475
  speech language pathology (SLP), 94*c*, 168–169, 682–688
  in spiritual assessment, 440
Laparoscopy, 201
Last Acts Partnership, 811
Latinos/Latinas. *See* Hispanic populations
Laxatives, 189–190
Lay health workers, 676–677
LEAN Six Sigma, 574
Left ventricular assist devices (LVADs), 565, 567–568*b*, 832
Legacy, leaving through social media, 463, 796
Legal considerations
  in assisted dying, 357, 830–831, 839–840
  delirium and, 327
  in medically administered nutrition and hydration, 211
  palliative sedation and, 357, 359
  in pediatric end-of-life decision-making, 737, 746
Leicester Cough Questionnaire, 224
Leisure education, 685
Lesbian populations. *See* LGBTQIA (lesbian, gay, bisexual, transgender, queer/questioning, intersex, and asexual) populations
Levomepromazine, 155
Levonantradol, 156
Levorphanol, 120*t*, 121–122
LGBTQIA (lesbian, gay, bisexual, transgender, queer/questioning, intersex, and asexual) populations
  families and, 406
  palliative care for, 498–499
  sexuality and intimacy, 341–342
  transgender patients, 475, 499*c*
L-glutamine, 367
Licensed clinical social workers (LCSW), 616–617
Licensed practical/vocational nurses (LPN/LVNs), 607–608
Life expectancy, in U.S., 483, 615
Life maps, spiritual, 439
Life reviews, 463
Lifestyle medicine, 362
Life-sustaining treatments
  advance directives and, 82
  definition, 737*b*
  discussions regarding, 69–71
  medical orders for, 83–84
  withholding and withdrawal of, 423–425, 567, 626, 629–631, 632*t*, 737*b*, 829–834, 830*c*, 840
Listening skills, 462. *See also* Communication
  active, 44, 62, 478
  cultural considerations and, 478
  pediatric care and, 804
  in spiritual assessment, 441
Liver transplant, 202
Living day to day, 409–410
Living wills, 82, 691–692, 826. *See also* Advance care planning
Living with Hope Program (LWHP), 387
Local anesthetics, 123–124, 124*t*
Long-term care facilities, 606–612. *See also* Nursing homes
  assisted living facilities, 606
  Continuing Care Retirement Communities, 606
  group homes, 606
  types of, 606–607
Lorazepam, 156, 314, 324, 358, 627
Loss. *See also* Bereavement; Grief; Mourning
  definition, 390
  hope and, 379
  "letting go" and, 399
  meaning and, 458–459
  older adults and, 485
  secondary, 784
  stages of grief and, 393
Lou Gehrig's disease. *See* ALS
Love, 453
Low- or middle-income countries (LMICs), 868–875
Lubricant laxatives, 190
Lunesta (eszopiclone), 335
Lung cancer, 218, 224, 348
Lung diseases. *See also* COPD
  palliative care, 552–557
Luxembourg, 838
LVADs. *See* Left ventricular assist devices (LVADs)
Lymphedema, 238–249
  assessment and diagnosis of, 240–242, 241*b*
  case studies, 241–242*c*, 244–246*c*
  definition, 238
  edema, compared to, 239*t*
  impact of, 239–240
  infection prevention and treatment, 247–248
  long-term management, 248–249, 248*b*
  pain management for, 248–249
  physiology and pathophysiology of, 240
  prevalence and risk factors for, 238
  quantification of, 242–243
  risk reduction, 243–244
  treatment, 246–248
  unusual and challenging sites of, 242, 249*b*
Lymphology Association of North America (LANA), 249
Lymphoma, case studies, 430*c*
Lymphorrhea, 249

macrolide antibiotics, 154–155
Magnesium, 367
Malignant bowel obstruction (MBO), 150, 186, 192–196, 203
  assessment, 192
  case studies, 192*c*, 196*c*, 663*c*
  definition, 192
  diagnostic studies, 193
  management, 193–196, 193*b*
  nursing interventions, 193–194

Malignant bowel obstruction (MBO) (*Cont.*)
  pathophysiology and risk factors, 192
  pharmacological management, 194–196
  physical examination, 192–193
  procedural management, 194
  surgical management, 194, 661–663
Malignant esophageal tumors, dysphagia resulting from, 166
Malignant fungating wounds (MFW)
  assessment, 268
  complementary alternative medicine, 269
  management, 266–269, 267*f*, 268*f*
  psychosocial aspects of care, 268–269
  spiritual aspects of care, 269
Malignant pleural effusions (MPEs), 664–665
Malnutrition, 140, 142, 146, 207. *See also* Nutrition
Malnutrition-inflammation-cachexia syndrome (MICS), 140, 141*t*
Mania, in bipolar disorders, 506–507
Manipulative and body-based methods. *See* Exercise and physical activity; Massage therapy
Man's Search for Meaning (Frankl), 36
Marcel, Gabriel, 379
Marijuana. *See also* Cannabinoids
  illicit use, rates of, 522
  medical, 781
Marjolin's ulcers, 269–270, 270*b*
Mary Giovanni, Sister, 844
Maslow's hierarchy of needs, 36, 46
Massachusetts, hospice policy, 801
Massage therapy
  for depression and anxiety, 315
  for nausea and vomiting, 158*t*
  for pain management, 364
  in pain management, 126
  prevalence of use, 361
Matter-of-fact telling, 785
MBO. *See* Malignant bowel obstruction
MBTs. *See* Mind-body therapies
McGill Pain Questionnaire-2, Short Form (SF-MPQ-2), 108
McGill University, 15
Meaning, well-being and, 822
Meaning in illness, 456–464
  bereavement and, 768
  brokenness and, 459–460
  case studies, 458*c*, 460*c*
  dark night of the soul, 459
  definition, 456–458
  depression and, 312
  for healthcare professionals, 463–464
  hope and, 397
  imposed transition and, 458
  loss and confusion, 458–459
  nursing interventions, 462–463
  patient-caregiver relationship and, 461
  process of finding, 458–460
  randomness and absence of God, 459
  reappraisal of, 460
  searching for, 409, 458–460
  spirituality and, 456–457, 459
  transcendence and, 461–462
Meaning of life, 456–458
Measured telling, 785
Measurement of outcomes, 813. *See also* Quality improvement (QI)
  in hospital-based palliative care, 27, 27*t*
  outcome indicators, 582, 585–586
  quality improvement (QI) and, 582–584
Measuring What Matters (MWM), 9, 577
Mechanical circulatory support devices (MCSD), 565
Mechanical insufflator-exsufflator (MIE), 172
Mechanical pneumatic pumps, 247
Mechanical ventilation (MV)
  benefits and burdens of, 371–372
  case studies, 371*c*
  in dyspnea, 222
  ethical considerations, 826
  extubation considerations and, 373
  organ donation and, 372, 549
  withdrawal of, 371–375, 630–631, 632*b*
Meclizine, 155
Medicaid. *See also* Centers for Medicare and Medicaid Services (CMS)
  access to care and, 801
  nursing home care and, 607
  pediatric palliative care and, 617, 712
  reimbursement from, 814
  rural populations and, 678
Medical adhesive-related skin injury (MARSI), 262–266, 267*t*
Medical insurance. *See* Health insurance
Medical marijuana, 781. *See also* Cannabinoids
Medical Order for Life-Sustaining Treatment (MOLST), 67, 83–84, 692, 827. *See also* Physician Order for Life-Sustaining Treatment (POLST)
Medical Research Council Dyspnea Scale, 220
Medically administered nutrition and hydration (MAHN), 206–214. *See also* Dehydration; Hydration; Nutrition
  benefits and burdens of, 207, 207*t*, 209
  case studies, 210–211*c*
  conversations about, 71, 214
  cultural considerations in, 479
  decision-making and, 211–214
  dysphagia and, 172, 207–208
  ethical considerations in, 211, 212*t*, 826, 829–830, 831*b*
  goals of care and, 214
  hunger and, 208
  imminent death and, 423–424
  initiating and withdrawing, 214
  malnutrition, anorexia, and cachexia, 207
  methods of administration, 207–209, 209*t*
  natural fluid deficits and, 206–207
  in nursing homes, 608
  nursing roles in, 214
  in pediatric palliative care, 704–705
  position statements and guidelines, 211, 211*t*, 212*t*
  pressure ulcers and, 208
  quality of life and, 208, 210
  religious and cultural issues, 211–214, 213*t*
  survival time and, 208, 210
Medicare. *See also* Centers for Medicare and Medicaid Services (CMS)
  aging population, 15
  community-based nursing, 620
  IAH innovation model, 617
  nursing home care, 607
  patient deaths in hospice, 251
  quality improvement and, 574
  reimbursement, 616–617, 693, 813–814
  rural populations and, 678
  users by location, 672*t*
Medicare Hospice Benefit (MHB), 5, 6
Medicare Modernization Act of 2003, 814
Medications. *See also* Pharmacological management of disease; *specific medications*
  assessment and, 40
  constipation resulting from, 187*b*
  dysphagia as side effect of, 168, 168*t*
  dysphagia patients, administration for, 173
  psychiatric patients' right to refuse, 510
  right to refuse, 510
  side effects of, 106
Meditation, 462
Megestrol acetate (MA), 144
Melatonin, 366
Melatonin-receptor agonists, 335
Memorial Delirium Assessment Scale (MDAS), 321
Memorial Pain Assessment Card (MPAC), 109
Memorial Symptom Assessment Scale, 142, 699
Memorial Symptom Assessment Scale (MSAS), 220
Mental health assessment, 35*t*. *See also* Psychosocial assessment
Mental illness, 503–511. *See also* Anxiety; Depression; Mood disorders; Psychotic disorders; Severe and persistent mental illness (SMPI)
  homelessness and, 492
  in older adults, 485
Metabolic alterations, 141
Metastatic spinal cord compression (MSCC), 232
Methadone, 120*t*, 121, 121*t*, 779
Methylnaltrexone, 191
Metoclopramide, 154, 191–192
MHB (Medicare Hospice Benefit), 5, 6
Microbial agents, 199
Midazolam, 358, 627
Middle adulthood, sexuality and intimacy, 341
Migraines, 297
Military patients. *See* Veterans
Mind-body therapies (MBTs), 362
  for gastrointestinal symptoms, 366–367
  for mood and sleep, 365–366
  for pain management, 364
Mindfulness, 315, 364, 462
Mindfulness-based stress reduction (MBSR), 223*t*, 364
Mini-Cog, 321*t*, 322
Mini-Mental State Examination (MMSE), 321*t*, 322
Minimum Data Set (MDS), 98, 576, 608, 609
Minnesota Rural Palliative Care Initiative (MRPCI), 675–676
Mirtazapine, 335
Miscarriage, 395
Moisture-associated skin damage (MASD), 258
MOLST. *See* Medical Order for Life-Sustaining Treatment
Montana, 837
Montreal Cognitive Assessment (MoCA), 321*t*, 322
Mood disorders, 309. *See also* Anxiety; Bipolar and related disorders; Depression
  complementary and integrative therapies for, 365–366
  occupational therapists and, 687
Moral dilemmas, 824
Moral distress, 762, 824, 834–835
Moral injury, 541–542
Moral uncertainty, 824
Morbidity, correlation with stress, 48–49
Morphine
  for cough, 224
  excretion of, 40
  for pain management, 120, 120*t*, 525
  ventilator withdrawal and, 631

Motor neuron disease
  dysphagia resulting from, 166
  sialorrhea and, 177
Motor skills, deficits in, 273–274
Mourning, 391–392. *See also* Bereavement; Grief; Loss
  definition, 390, 759
Mu opioid receptors, 191
Mucocutaneous separation, 276, 276*f*
Multidimensional Assessment of Fatigue, 135
Multidimensional Dyspnea Profile (MDP), 220
Multidimensional model for pain assessment, 104–110, 105*t*
Multi-dimensional Objective Pain Assessment Tool (MOPAT), 112*t*
Multilayer lymphedema bandaging (MLLB), 247
Multimorbidity, HIV and, 515
Multinational Association of Supportive Care in Cancer and European Society for Medical Oncology (MASCC/ESMO), 156–157
Multiple myeloma, 153–154*c*, 187, 350
Multiple sclerosis (MS), 132–133, 133*b*, 167, 303
Multiple system atrophy (MSA), 166–167
Muscular dystrophy (MD), 304–306
Music therapy
  for nausea and vomiting, 158*t*
  for pain management, 126, 364
  in pediatric palliative care, 701
  prevalence of use, 361
MV. *See* Mechanical ventilation
Myasthenia gravis (MG), 303–304
Myoclonus, 123, 210, 293–295
Myopathy, dysphagia resulting from, 167
Mystery, 450

Nabilone, 156
Nalbuphine, 778
Naldemedine, 191
Naloxegol, 191
NAM. *See* National Academy of Medicine
Naoloxone, 191
Naproxen, 119*t*
Narcissistic personality disorder, 508
Narrative ethics, 825
"Narrative Matters," 804
Nasogastric tubes (NGT), 193, 207, 209, 662
National Academy of Medicine (NAM; formerly Institute of Medicine, IOM), 27. See also *Dying in America*
  on anxiety in communication, 60
  on bereavement, 758
  The Future of Nursing, 10, 810, 849
  on nursing home care, 607
  on pediatric palliative care, 713
  on pulmonary palliative care, 552
National Alliance on Mental Illness (NAMI), 511
National Association of Catholic Chaplains, 9
National Association of Neonatal Nurses (NANN), 753
National Board for Certification of Hospice and Palliative Nurses (NBCHPN), 19, 813
National Cancer Institute, 364
  Common Toxicity Criteria, 197, 198*b*
National Center for Complementary and Integrative Health (NCCIH), 535
National Coalition for the Homeless, 491
National Coalition of Hospice and Palliative Care, 5
National Comprehensive Cancer Network (NCCN)
  Distress Thermometer, 435
  fatigue practice guidelines, 133–138
  on nausea and vomiting, 149, 156–157, 159
  pain guidelines, 100
  standards of care, 26
  survivorship guidelines, 535
National Consensus Project (NCP), 90, 811. See also *Clinical Practice Guidelines for Quality Palliative Care*
  definition of palliative care, 285
  on nursing education, 620
  on psychological and psychiatric care, 309
  on quality improvement, 27
  on spirituality, 433
  standards for palliative care, 17
National Council Licensure Exam for RNs (NCLEX-RN), 812, 845
National Council of State Boards of Nursing (NCSBN), 620, 809, 845
A National Framework and Preferred Practices for Palliative and Hospice Care Quality (NQF), 5–6, 811–812
National Home and Hospice Survey, 251
National Hospice and Palliative Care Organization (NHPCO), 361
  advocacy information online, 804
  hospital-based palliative care and, 20, 21–22
  National Consensus Project and, 811
  pediatric curriculum, 724
  public policy and, 29
  standards of practice, 709–712*b*
National Institute of Nursing Research (NINR), 844, 855, 857–859
National Institutes of Health (NIH), 29, 362, 693
  palliative care research, 29, 855, 857–859
  quality improvement, 573
National Lymphedema Network, 247
National Organ Transplant Act (NOTA), 546
National Palliative Care Research Center (NPCRC), 20
National Pressure Ulcer Advisory Panel (NPUAP), 254, 263*t*
National Society of Genetic Counselors, 41
Native Americans. *See* American Indians/Alaska Natives
Natural Medicines database, 535
Natural products, 362, 367–368*t*
  for gastrointestinal symptoms, 367
  for mood and sleep, 366
  for pain, 364–365
  resources for, 367
Naturopathic medicine, 363
Nausea and vomiting, 149–160
  anticipatory, 150, 159
  assessment of, 152–154, 153*b*, 153*t*
  cancer population, 150
  case studies, 153–154*c*, 704*c*
  causes of, 151–152, 152*b*
  chemotherapy-induced, 150
  in children, 703–704, 719
  conceptual concerns related to, 150
  definition, 150
  dyspnea and, 219
  epidemiology of, 149–150
  home hospice approach to selecting antiemetics, 157
  noncancer population, 150
  nonpharmacological management, 157–159, 157*b*
  nursing interventions for, 159
  from opioid analgesics, 123
  pharmacological management, 154–157, 154*b*
  physiological mechanisms of, 151
NBCHPN. *See* National Board for Certification of Hospice and Palliative Nurses
NCCN. *See* National Comprehensive Cancer Network; National Comprehensive Cancer Network (NCCN)
NCP. *See* National Consensus Project
Neck cancer, 249*b*
Neck lymphedema, 249*b*
Needs, hierarchy of, 36, 46
Neonatal intensive care unit (NICU), 749–756
Neoplasms, 165–166
Nephrology, outpatient palliative care and, 645–646
Nervous system, dying process and, 356
Netherlands, 838
Neuro-irritability assessment, 705*b*
Neuroleptics, 195. *See also* Antipsychotics
  for insomnia, 335
Neurological disorders, 291–306. *See also* ALS; Parkinson's disease (PD)
  in children, 705
  headaches, 297–298
  impaired communication, 298
  multiple sclerosis, 132–133
  myoclonus, 293–295
  seizures, 291–293
  spasticity, 295–297
  terminology, 292*t*
Neuromuscular blocking agents (NMBA), 372
  pain assessment and, 625
  ventilator withdrawal and, 631
Neuromuscular diseases
  dysphagia resulting from, 166–167
  outpatient palliative care and, 646
  stoma care and, 274*t*
Neuropathic pain, 99, 102
  in children, 779
Neuropathy, 533
New York, 811
NHPCO. *See* National Hospice and Palliative Care Organization
Nick Snow Act, 801
NIH. *See* National Institutes of Health
NK-1 receptor antagonists, 156–157
N-methyl-D-aspartate (NMDA), 124, 124*t*, 126*b*
Nociceptive pain, 99
Nonbenzodiazepine receptor agonists, 335
Noninvasive ventilation (NIV), 554–555
Nonmaleficence, 211, 357, 839, 856
Nonopioid analgesics, 118
Nonpharmacological management of disease, 126
  anxiety, 628
  cancer survivorship, 535
  delirium, 325–327
  dysgeusia, 182
  dyspnea, 222–223, 223*t*
  fatigue, 136–138
  hiccups, 174
  insomnia, 333, 334*t*
  nausea and vomiting, 157–159, 157*b*, 158*b*
  pain management, 126, 627
  pediatric pain, 776*t*
  pruritus, 286
  severe and persistent mental illness (SMPI), 505, 507
  xerostomia, 179, 180–181*t*

Nonsteroidal anti-inflammatory drugs (NSAID), 118, 119*t*
Nonverbal communication, 56, 440
Nonverbal patients, pain assessment in, 110–113, 110*t*, 111*b*, 112–113*b*, 625, 699, 775
North Carolina, 678
Norton Scale, 260
Now I Lay Me Down to Sleep organization, 756
NQF (National Quality Forum)
  hospital-based palliative care, 20, 21, 27
  National Framework and Preferred Practices for Palliative and Hospice Care Quality, 5–6, 811–812
  on palliative care, 251
  on quality improvement, 27, 575–576
  on spirituality, 433
  standards for primary palliative care, 17
Numeric Rating Scale (NRS), 107, 107*f*, 109*t*, 220, 773
NURSE model for communication, 62
Nurse practitioners (NPs), 608
Nurses, roles and interventions. *See also* Occupational stress; Self-care
  advance care planning, 67, 84–85
  advocacy for patients and families, 861–866
  bereavement, 400–401, 764–770
  bowel management, 201
  chemotherapy, 667
  communication, 56–59, 74
  diarrhea, 198–199
  family-centered palliative care, 411*t*
  fostering hope, 385–387, 385*b*
  geriatric palliative care, 486–488
  global palliative care, 875
  hemoptysis, 348
  hiccups, 175
  hypercalcemia, 352
  insomnia, 332–333
  integrative medicine, 361
  on interdisciplinary teams, 91, 92–93*c*
  life-sustaining treatment discussions, 70–71
  malignant bowel obstruction, 193–194
  meaning in illness, 462–464
  medically administered nutrition and hydration, 214
  nausea and vomiting management, 159
  nurse-patient relationships, 41, 55–75, 57*t*
  for oral symptoms, 176
  palliative care, 9–10, 56–59
  palliative chemotherapy, 667
  palliative sedation, 359
  palliative surgery, 667
  patient education, 316
  pediatric end-of-life decision-making, 734, 743*t*, 746–747
  pediatric hospice, 804
  pediatric palliative care, 804
  pleural effusions, 347
  scheduled meetings, 65
  social media, 796–797
  spinal cord compression, 348
  teamwork, 74
  wound, ostomy, and continence (WOC) care, 252, 252*b*
Nursing advocacy. *See* Advocacy in palliative nursing
Nursing education, 844–852
  advanced specialty training in palliative care, 19–20
  barriers in, 848–849
  for community-based palliative care, 620–621
  death education, 634
  guidelines and standards, 812–813
  interdisciplinary, 18–20
  international, 851
  opportunities in, 848–849
  on pediatric palliative care, 724
  quality of care and, 586
  sharing narratives, 634
Nursing Home Compare website, 607
Nursing Home Reform Act of 1987, 607
Nursing homes, 606–612
  advance care planning in, 610
  case studies, 611–612*c*
  challenges to palliative care delivery, 608
  end-of-life transitions in, 610–611
  ethical considerations in, 608
  external consultation teams in, 609
  facilitators to palliative care delivery, 608–609
  history and growth of, 607
  hospice care in, 609
  integrated palliative care in, 610
  interdisciplinary care teams in, 607–608
  models of palliative care delivery, 609–610
  resources for enhancing palliative care in, 611
  types of, 606–607
Nursing research. *See* Research in palliative care
Nutrition. *See also* Dehydration; Drinking; Feeding tubes; Food; Hydration; Medically administered nutrition and hydration
  for anorexia/cachexia syndrome, 143–144
  assessment of, 142–143
  cultural considerations in, 479
  dysphagia and, 170–171, 171*t*, 172*b*
  enteral feeding, 144
  fistulas and, 279
  parenteral, 144

OACIS Lehigh Valley Health Network, 616
Obamacare. *See* Patient Protection and Affordable Care Act of 2010
Obsessive-compulsive personality disorder, 508
Occupational stress, 817–818. *See also* Burnout; Compassion fatigue; Self-care
Occupational therapy (OT), 94*c*, 682–688
Octreotide acetate, 156
Oculopharyngeal muscular dystrophy (OPMD), 167
Odor control, for wounds, 256–257, 260*t*
Office of End-of-Life and Palliative Care Research, 855
Olanzapine, 155
Old Age Assistance (OAA) program, 607
OLDCARTS pain history mnemonic, 774*b*
Older adults, 483–488. *See also* Aging
  case studies, 484*c*, 487*c*
  chronic conditions, 484
  cultural considerations, 474
  falls, 485*b*
  functional status, 485*b*
  geriatric syndromes, 485*b*
  hope in, 381
  housing, 486
  living arrangements, 486
  palliative care for, 483–488
  physical well-being, 484–485
  psychological well-being, 485–486
  sexuality and intimacy, 341
  social well-being, 486
  spiritual well-being, 486
Omega-3 fatty acids, 365
Omnibus Budget Reconciliation Act of 1986, 546
Omnibus Budget Reconciliation Act of 1989 and 1990, 814
Omnibus Reconciliation Act of 1987 (OBRA-87), 607
Oncology. *See* Cancer
Ondansetron, 155
Online resources, 675–676, 700–701*b*. *See also* Internet; Social media; Web technology
Opioid Risk Tool, 523
Opioid use disorders (OUD), 522–528, 811
  in intensive care unit, 626
Opioid-induced myoclonus (OIM), 294–295
Opioid-Related Behaviours in Treatment (ORBIT) scale, 106
Opioid-related deaths, 646–647, 871
Opioids, 99–100, 104, 106–107
  adverse effects of, 122–123
  cannabinoids and, 365
  delirium and, 210
  for diarrhea, 199
  for dyspnea, 222, 702
  global distribution and need, 872*f*
  guidelines, 100, 104, 526–527, 647*b*
  in intensive care unit, 626*t*
  for malignant bowel obstruction, 195–196, 662
  in outpatient palliative care, 646–648*t*, 647*b*
  for pain management, 118–122, 119*b*, 120*t*, 121*t*
  palliative sedation and, 358
  pediatric pain and, 778, 780
  pruritus and, 288
  for respiratory distress, 372–373
  safe storage of, 527–528
  for spinal cord compression, 350
Opportunistic infections and malignancies, with HIV/AIDS, 196–197
Optimizing Patient Transfers, Impacting Medical Quality, and Improving Symptoms: Transforming Institutional Care (OPTIMISTIC), 610–611
Opus Peace organization, 541*b*, 542–543
Oral feeding, 172*b*, 608
Oral hygiene, 176
Oral medications, 173
Oral Secretion Scale (OSS), 177*b*
Oral symptoms, 175–182. *See also* Sialorrhea (excess oral secretions); Xerostomia (dry mouth)
  anorexia and, 142
  assessment of, 176
  case studies, 175*c*
  nursing interventions, 176
  pathophysiology of saliva production, 176
  in serious illness, 175–176
Oregon, 837–841
Orexin receptor agonists, 335
Organ and tissue donation, 545–550
  aftercare services, 549
  attitudes and perceptions, 546
  brain dead donation, 548–549
  case studies, 549–550*c*
  clinical trigger for, 546–547
  discussion with family, 425, 547
  donation after circulatory death (DCD), 549
  donor designation, 547
  electronic health records and, 39
  organ recovery surgery, 549, 550*f*
  palliative care and, 546–548
  referral process, 547
  ventilator withdrawal and, 372, 549

Organ Procurement and Transplantation Network (OPTN), 546
Organ Procurement Organizations (OPO), 372
Organ transplants, 493
Orientation, delirium and, 326
Oropharyngeal dysphagia, 166. *See also* Dysphagia
Osher Collaborative, 362
Osmotic laxatives, 190
Osteoporosis, 352
Ostomy. *See* Wound, ostomy, and continence (WOC) care
Outcome indicators, 575, 582, 585–586. *See also* Measurement of outcomes; Quality improvement (QI)
Outpatient palliative care, 639–648
  benefits and challenges in, 640–641
  benzodiazepines in, 646–647
  cardiology and, 644–645
  case studies, 647*c*
  clinical measures used in, 643
  components of care visits, 643
  funding for, 643–644
  gerontology and, 646
  interdisciplinary teams, 89
  length of care visits, 643
  models of, 640
  nephrology and, 645–646
  neuromuscular diseases and, 646
  oncology and, 644
  opioid management in, 646–648*t*, 647*b*
  patient education in, 644
  primary, secondary, and tertiary care, 640
  pulmonology and, 645
  referrals to care team, 641–643
  research studies on, 639
  substance use disorders and, 646–647
  team members in, 641
  telephone support in, 644
Ovarian cancer, 244–245*c*
Oxycodone, 120*t*, 121, 191
Oxygen, 374
Oxygen therapy, 222
Oxymorphone, 121

Pacific Islanders. *See* Asian/Pacific Islander populations
Pain. *See also* Pain assessment; Pain management; Suffering
  acute, 99
  aggravating and alleviating factors, 102–103
  behaviors, 110, 110*t*, 111
  from cancer, 99*c*
  chronic, 99
  definition, 98
  delirium and, 326
  descriptors of, 103, 103*t*
  duration of, 102
  end-of-dose failure, 102
  headaches, 297–298
  heart failure and, 566
  HIV/AIDS and, 514
  intensity of, 102
  location of, 102
  mnemonics, 101, 102*t*
  neuropathic, 99, 102
  nociceptive, 99
  pediatric (*See* Pediatric pain)
  persistent, 99
  prevalence of, 98, 116
  total pain, 103, 256, 256*b*
  types of, 98–99
  underreported, 105
  undertreatment of, 98, 99
  wound-related, 255–256, 255*b*
Pain assessment, 98–113. See also *specific assessment measures*
  5 A's and, 106*t*
  age and, 104–105
  barriers to, 99, 100*b*, 101*t*
  behaviors and, 110–113, 110*t*, 111*b*, 112*t*
  case studies, 99*c*, 103–104*c*
  in cognitively impaired patients, 110–113, 110*t*, 111*b*, 112–113*b*
  cultural considerations in, 479
  ethnicity and, 105, 110
  financial status of patient and, 106
  gender and, 105
  guidelines and standards for, 100–101
  history, 101
  intensity scales for, 107–108*f*, 107–111, 109*t*
  in intensive care unit, 625
  malignant fungating wounds, 269
  marital status/social support and, 105
  multidimensional instruments for, 108–110
  multidimensional model for, 104–107, 105*t*, 106*t*
  in nonverbal patients, 110–113, 110*t*, 111*b*, 112–113*b*, 625, 699, 775
  pain management and, 117–118
  past experiences and, 106
  patient self-report, 101–104
  pediatric, 773–775
  physical examination, 101
  proxy pain, 111–113
  sociocultural dimension, 104–107
  spirituality and, 106
  substance abuse and, 106–107
  treatment and, 113
  wounds, 255–256
Pain Assessment Behavioral Scale (PABS), 113*t*
Pain Assessment in Advanced Dementia (PAINAD), 113*t*
Pain management, 116–128. *See also* Analgesics
  barriers to, 116, 117*b*
  case studies, 127–128*c*
  complementary and integrative therapies, 363–365
  cultural considerations in, 479
  effects of unrelieved pain, 117
  guidelines for, 127*b*
  healthcare providers and, 116–117
  healthcare settings, 117
  in intensive care unit, 625–627
  interventional therapies, 125–126
  nonopioid, 123–126
  nonpharmacological, 126, 627
  occupational and physical therapy for, 686
  pain crisis, 126
  patients and families and, 117
  pediatric, 773, 775–781
  pharmacological, 118–126, 626–627, 628*t*
  principles of, 126–128
  refractory symptoms at end of life, 126–127
  routes of administration, 122
  for spinal cord compression, 350
  for substance use disorder patients, 127, 521–529
PALCARE (wound care), 253*b*, 268*f*
Palliative and Supportive Medicine Consult Tool, 24–25*f*
Palliative care
  for children (*See* Pediatric palliative care)
  costs of, 692–693
  definition, 6–7, 15–16, 251, 285
  domains of, 6*b*, 7–9, 7*b*
  improvement of (*See* Quality improvement)
  models of, 89, 90*t*, 94–95
  role of nurse in, 56–59 (*See also* Nurses, roles and interventions)
Palliative Care and Hospice Education and Training Act (PCHETA), 29, 693
Palliative Care Certification Manual (Joint Commission), 21
Palliative Care Clinical Guidelines (NCCN), 26
Palliative Care for Advanced Disease (PCAD) pathway, 577–578, 578*b*, 578*t*, 596–602*f*
Palliative Care Leadership Centers (PCLC), 678
Palliative care nurses (PCN), role on interdisciplinary teams, 91, 92–93*c*
Palliative care physician, role on interdisciplinary team, 91, 93*c*
Palliative Care Research Cooperative, 855
Palliative care social workers (PCSW), role on interdisciplinary teams, 91, 93*c*
Palliative care teams (PCT), 89–96. *See also* Interdisciplinary teams (IDT)
Palliative care units (PCU), 18
Palliative chemotherapy, 665–667
  case studies, 666
  clinical trial participation, 666
  decision-making and goals of care, 665–666
Palliative Nursing Manuals (HPNA), 10
Palliative Outcome Scale, 582
Palliative Performance Scale (PPS), 35, 45*b*, 46, 48, 53, 53*b*
Palliative sedation, 356–359
  ethical considerations in, 831*b*, 832–833
  goal of, 357
  in intensive care unit, 627
  legal and ethical considerations in, 357, 359
  opioids and, 122
  proportionate, 357–358, 832
  for refractory symptoms, 356–359
  to unconsciousness (PSU), 832–833
  ventilator withdrawal and, 630–631
Palliative surgery, 660–665
  case studies, 663*c*
  common indications for, 661–665
  decision-making in, 660, 661*f*
  family caregivers and, 660
  goals of care, 660, 661*f*
  lymphedema, 246
  nursing roles in, 667
Palonosetron, 155
Pamidronate, 351
Paracentesis, 201–202
Paradox, struggling with, 409
Paranoid personality disorder, 508
Parapneumonic disease, 346
Parenteral dosing, 122, 126
Parenteral nutrition, 144
Parenteral nutrition and hydration, 209
Parents. *See also* Families; Family-centered palliative care; Patient and family assessment; Pediatric palliative care (PPC)
  grief and grief interventions for, 400, 758–770
  in hospice, support for adolescents of, 783–789
  parent-child relationships, 759–761
  pediatric decision-making, 736–747
  pediatric palliative care, involvement in, 715–718
  spiritual assessment, 442–443
Pareto Principle, 575
Paristomal varices *(caput medusae),* 276, 276*f*

Parkinsonism, 299
Parkinson's disease (PD), 299–301
  case studies, 429–430*c*
  constipation and, 187
  dysphagia resulting from, 166
  pain behaviors and, 110
  sialorrhea and, 177
Particularized hope, 379
Pathological fractures, 352–353
Patient, model case example of, 3–4
Patient advocacy, 861–866
Patient and family assessment, 32–53, 763
  during active dying, 49–53, 50*t*, 51*t*, 52*b*, 53*b*
  after treatment, 48–49
  in ambulatory settings, 53*b*
  of anxiety, 47*t*
  case studies, 33*c*, 46*c*, 47–49*c*, 53*c*
  chronic and life-threatening illnesses, 32–33, 33*t*
  communication techniques in, 40–41
  cultural competence in, 37
  of depression, 35*t*
  at diagnosis, 41–46
  electronic health record review and, 38–40
  for funeral plans, 53*b*
  grief, 35*t*
  grief and, 44
  importance of, 32
  initial face-to-face encounter, 40–41
  interpreter services and, 37–38*b*
  mental health assessment, 35*t*
  nursing database and, 41
  physical assessment, 34–35, 41–45*b*, 46, 48, 50
  principles of, 53
  psychosocial, 34*t*, 35–36, 44–50
  self-awareness and, 32, 33*b*
  spiritual assessment, 36–37, 37*b*, 45–48, 50–53
  during treatment, 46–48
Patient and family meetings, 64–65, 65*b*
Patient education
  anxiety and depression, 316–317
  constipation management, 188–189
  in outpatient palliative care, 644
Patient Health Questionnaire 2 (PHQ2), 269*b*
Patient Health Questionnaire 9 (PHQ9), 310
Patient Protection and Affordable Care Act of 2010, 607, 737, 801, 811, 856
Patient satisfaction with quality of care, 582–586
Patient Self-Determination Act (PSDA) of 1990, 39, 80, 211, 478, 826
Patient-centered palliative care, 9, 29, 751*b*
  in assessment, 41
  older adults and, 485–486
  principles of, 709–712*b*
  recommendations on, 691
Pausch, Randy, 36
Payment systems, 692–693
Payne-Martin classification tool, 262
PD. *See* Parkinson's disease
"Pediatric Concurrent Care," 712
Pediatric end-of-life decision-making
  case studies, 727–729*c*, 732*c*, 733–734*c*
  child participation in, 737, 744–745
  ethical and legal considerations in, 737, 746
  goals of care, changes in, 727–734
  healthcare provider considerations in, 740–741
  nursing roles in, 734, 743*t*, 746–747
  parental involvement in, 729–734, 738–743, 745, 745–746*b*
  in pediatric oncology, 741–743
  uncertainty and, 728–734
  value-based decision-making and, 733
Pediatric hospice, 708–725. *See also* Pediatric palliative care (PPC)
  access to, 800–804
  delivery of care, 802
  nursing roles in, 804
  palliative care vs., 709–712, 800
  quality of care, 803–804
  special populations, 803
  utilization of care, 802–803
Pediatric pain, 773–781
  acute, 776, 777–778*t*
  assessment of, 773–776*t*
  case studies, 774*c*, 778*c*, 779–781*c*
  chronic, 780–781
  neurologic impairment and, 775
  neuropathic, 779, 780*t*
  nonpharmacological management, 776*t*
  pharmacological management, 776–781
  two-step strategy, 776–777
Pediatric palliative care (PPC), 699–725. *See also* Children and adolescents; Pediatric end-of-life decision-making; Pediatric hospice
  access to, 714, 800–804
  assessment, 699–701, 714
  barriers and challenges, 712–715
  case studies, 703*c*, 706, 727–729*c*, 732*c*, 750–751*c*, 754*c*
  communication in, 699, 718, 730–733
  community-based care, 617, 800
  components of care, 718–719
  concurrent care in, 712–713
  death, care at time of, 722–724, 753–755
  definition, 708–709
  delivery of care, 802
  ethical considerations in, 714–715, 722
  family-centered care in, 709–712*b*, 715–718
  features of, 716–718
  goals of care, 701, 727–734
  grief and bereavement in, 758–770
  health characteristics influencing use of, 803
  hope in, 721–722
  hospice care vs., 709–712, 800
  interdisciplinary teams in, 716–717
  nonpharmacological management, 701–704
  nursing considerations in, 715–716, 723–726
  nursing roles in, 804
  pain and symptom management, 699–706, 715, 718–719
  parental priorities for, 715–716
  perinatal, 722, 749–756
  pharmacological management, 702, 752*t*
  psychological care, 719–721
  quality of care, 803–804
  religious and spiritual considerations in, 721
  school interactions and, 718
  settings for, 713–714
  siblings and, 718
  social aspects, 721
  special populations, 803
  support services in, 717–718
  utilization of care, 802–803
  website resources, 700–701*b*
PEG (percutaneous endoscopic gastrostomy) tubes, 144
Pennsylvania, 676
People living with HIV (PLWH), 513–519. *See also* HIV/AIDS
Percutaneous endoscopic gastrostomy jejunostomy (PEG-J) tubes, 207
Percutaneous endoscopic gastrostomy (PEG) tubes, 144, 207
Performance improvement. *See* Quality improvement (QI)
Performance indicators, 579–586
Perinatal palliative care, 9, 749–756
  grief and, 764
Perioperative settings, family caregivers and, 415
Peripheral neuropathy, 779
Peripherally acting mu opioid receptor antagonists (PAMORAs), 191
Peristomal moisture-associated dermatitis, 276–277
Peristomal skin complications, 275–277
Peritoneal Disease, 200
Periwound moisture-associated dermatitis, 258
Perometer, 243, 244*f*
Persistent pain, 99. *See also* Pain
Personality disorders (PDs), 508–510
Pet therapy, 361
Pharmacogenomics, 101
Pharmacological management of disease. *See also* Medications; *specific medications*
  agitation and restlessness, 627, 628*t*
  anorexia/cachexia syndrome, 144–145, 145*t*
  anxiety, 313–314, 627, 628*t*
  ascites, 201
  constipation, 189–192
  delirium, 324–325
  depression, 313–314
  diarrhea, 199–200
  dysgeusia, 181–182, 181*t*
  dyspnea, 222
  fatigue, 136
  heart failure, 563–565
  hiccups, 175, 175*t*
  insomnia, 333–335
  malignant bowel obstruction, 194–196
  malignant bowel obstruction (MBO), 194–196
  nausea and vomiting, 154–157, 154*b*
  pain, 118–126, 626–627, 628*t*
  pediatric pain, 776–781
  pruritus, 286–287
  severe and persistent mental illness (SMPI), 504–507, 510
  xerostomia, 180*t*
Phase I study, 737*b*
Phenobarbital, 358
Phenothiazines, 155
PHQ2 (Patient Health Questionnaire 2), 269*b*
PHQ9 (Patient Health Questionnaire 9), 310
Physical activity. *See* Exercise and physical activity
Physical assessment
  during active dying, 50, 50*t*
  after treatment, 48
  at diagnosis, 41–44
  during treatment, 46
Physical examination, 45*b*
Physical therapy (PT), 94*c*, 682–688
Physician assistants (PAs), 608, 616
Physician Order for Life-Sustaining Treatment (POLST), 39, 67, 83–84, 84*t*, 493*c*, 692, 827. *See also* Medical Order for Life-Sustaining Treatment (MOLST)

Physician-aid-in-dying (PAD), 830–831, 837–841. *See also* Assisted dying
Physician-assisted suicide (PAS), 357, 830–831, 834. *See also* Euthanasia
Physicians Assistants Association, 9
PI. *See* Pressure injury
Pinterest, 791
Piper Fatigue Scale, 135
Place of residence, 476–477
Planet Cancer (website), 796
Planning for actual death, 420–430. *See also* Advance care planning
  cardiovascular implantable electronic devices, 424
  care of body after death, 427–429
  case studies, 429–430*c*
  CPR and, 423
  death rituals, 425–427
  determining occurrence of death, 427
  fluid administration and, 423–424
  focus of care, 423–424
  imminent death, signs and symptoms of, 425, 426–427*t*
  medications and, 424
  renal dialysis and, 424–425
  vital signs and, 423
Pleural effusions, 345–347
Pleurectomy, 347
Pleurodesis, 347
PLWH. *See* People living with HIV
Pneumatic (mechanical) pumps, 247
Pneumonia, 219
POLST. *See* Physician Order for Life-Sustaining Treatment
Poor populations, 490–500. *See also* Homeless populations; Poverty
  advanced disease in, 495
  assessment, 497–498
  barriers and challenges to palliative care, 496–497
  cancer and, 493–494
  case studies, 493*c*, 495*c*, 496*c*
  community and policy level approaches to, 497–498
  evidence-based palliative care for, 497
  health disparities, 493–495
  health problems, 492
  quality of life, 493–495
  therapeutic relationships with, 497–498
Portal hypertension, 200
Positive emotions, 821–822
Positive relationships, 822
Postmortem care of body, 427–429
Postmortem decomposition, 428
Postpartum care, 755
Post-traumatic stress disorder (PTSD), 492, 540–544
  intensive care units and, 632
Postural modifications, for dysphagia, 169, 171*t*
Poverty, 491. *See also* Poor populations
Power of attorney. *See* Durable power of attorney for healthcare
PPACA. *See* Patient Protection and Affordable Care Act of 2010
PPC. *See* Pediatric palliative care
PPI (Present Pain Intensity Index), 108, 195
PR programs, 222–223
Prayer, 463, 787
  pain management and, 126
Precursors Study, 690
PREPARE for Your Care, 82
Prescription drug monitoring program (PMDP), 526
Prescription Drug Use Questionnaire (PDUQ), 526
Presence, 450, 462, 478, 879–880
Present Pain Intensity Index (PPI), 108
Pressure injury (PI), 251
  avoidable, 254–255
  prevention of, 685
  risk assessment, 259–262, 264*t*
  risk factors and risk reduction, 259–262, 265*t*
  staging system, 263–264*t*
  term change from "pressure ulcers," 259
  treatment, 262, 265*t*
  unavoidable, 255
Pressure ulcers. *See also* Pressure injury
  management, 255
  medically administered nutrition for, 208
  term changed to "pressure injury," 259
Primary care practices, 617
Primary palliative care, 7, 17, 849
Prisons, palliative care in, 477
Privacy issues, 38
Private duty nursing agencies, 617
Probiotics, 192
Procedural pain, 625–626
Process indicators of performance, 581
Prochlorperazine, 155
Professional education, 692. *See also* Nursing education
Prognosis discussions, 69
Progressive muscle relaxation (PMR), 159, 367
Progressive supranuclear palsy (PSP), 166
Project ECHO (Extension for Community Healthcare Outcomes), 674
Project ENABLE, 675
Prokinetic agents, 154–155
Prolonged grief, 394. *See also* Complicated bereavement and grief
Promethazine, 155
Propofol, 358–359, 625, 627
Proportionate palliative sedation, 357–358, 832
Prostate cancer, 232*c*
Protection, 327
Protestantism, mourning in, 391–392
Protoclysis, 209
Proxemics, 56
Proxy decision-making, 828–829
Proxy pain assessment, 111–112
Pruritus, 256, 285–288
  assessment, 285
  case studies, 286*c*
  nonpharmacological management, 286
  opioids and, 123
  pharmacological management, 286–287
Pseudoaddiction, 524
Psychological problems, 309. *See also* Anxiety; Depression; Mental illness; Severe and persistent mental illness
  homelessness and, 492
  of older adults, 485–486
  poverty and, 492
Psychosocial assessment
  during active dying, 50
  after treatment, 48–49
  at diagnosis, 44–45
  framework for, 34*t*
  during treatment, 46–47
  for urban poor, 498*b*
Psychosocial interventions
  anorexia/cachexia syndrome, 142, 145
  bladder management, 235
  for poor populations, 496*t*
Psychostimulants, 313–314
Psychotherapy, 314–315, 505
Psychotic disorders, 504–506. *See also* Severe and persistent mental illness
PTSD. *See* Post-traumatic stress disorder
Public education and engagement, 693
Public policy, 692–693
  hospital-based palliative care and, 29
Pulmonary cachexia syndrome, 140, 141*t*
Pulmonary embolism, 219
Pulmonary hypertension medications, 554
Pulmonary palliative care, 552–557
  advanced ventilatory technology, 554–555
  case studies, 556–557*c*
  forecasting and, 555
  medication and, 554
Pulmonology, outpatient palliative care and, 645

QOL. *See* Quality of life
QOPI (Quality Oncology Practice Initiative), 27
Quality improvement (QI), 573–586
  Beth Israel Medical Center pilot study, 588–605*f*
  care path, 591–594*f*
  definition, 573
  history of, 574
  in hospital-based palliative care, 16, 27
  outcome indicators, 582, 585–586
  performance indicators, 579–586
  process indicators, 585
  satisfaction measurement and, 582–584
  standards of care and, 580–581, 619
  structural indicators, 585
Quality of life (QOL)
  discussions on, 70, 70*b*
  family caregivers, 412
  fatigue and, 132
  lymphedema and, 239–240
  medically administered nutrition and, 208
  nausea and vomiting and, 149, 153, 157, 159–160
  oral symptoms and, 182
  palliative rehabilitation and, 687–688
  pediatric, 727
Quality Oncology Practice Initiative (QOPI), 27
Queer/questioning populations. *See* LGBTQIA (lesbian, gay, bisexual, transgender, queer/questioning, intersex, and asexual) populations
Quetiapine, 314, 324
Quinlan, Karen Ann, 211, 840

Race, 473, 479, 500. *See also* Cultural considerations; *specific racial and ethnic groups*
  health disparities and, 493
Radiation therapy
  for bone metastasis, 353
  dermatitis resulting from, 271–272, 271*f*, 272*f*, 272*t*
  lymphedema and, 240
  for pain management, 125
  for spinal cord compression, 350
Radiofrequency ablation (RFA), 353
Radiopharmaceuticals, 125
Randomness, 459
Rational thought process interventions, hope and, 387
Reality surveillance, 383

Real-time audio/video communication, 674*b*
Recreation therapy, 683
Rectal suppositories, 190
Reflexology, 126
Refractory symptoms
  breathlessness, 217
  palliative sedation for, 126–127, 356–359
Reframing, 126
Registered dietitian/nutritionist (RDN), 94*c*
Registered nurses (RN), 10, 607–608
  billing and reimbursement for, 616–617
  in pediatric hospice, 802
  role on interdisciplinary teams, 91
Rehabilitation, 682–688
  case studies, 682*c*, 684*c*, 685–688*c*
  communication and collaboration in, 684, 685
  disability treatment plans, 684–686
  leisure education, 685
  occupational therapy, 683, 685
  physical therapy, 683, 684
  recreation therapy, 683, 685
  speech language pathology, 683, 685, 686
Reiki, 366
Reimbursement, 616–617, 693, 813–814
Relapse
  decision-making and, 741–742
  prevention, 525–527
Relational process interventions
  advocacy and, 863
  hope and, 386–387
Relationship level of communication, 56
Relationships
  family dynamics and, 761–762
  grief and, 759–762
  positive, 822
  social capital and, 792
Relaxation techniques, 126
Reliability, 878
Religion. *See also* Spirituality; *specific religions*
  cultural influences on, 475
  definition, 447
  language, 440
  and medically administered nutrition and hydration, 211–214
  mourning and, 391–392
Remote monitoring, 674
Renal dialysis. *See* Dialysis
Renal disease. *See* End-stage renal disease (ESRD)
Renal Physicians Association, 9*b*
Renal replacement therapies, 565
Research in palliative care, 855–860
  benefits and challenges in, 856–857
  funding sources, 858
  goals of, 855–856
  preparation of proposals, 859
  priority research areas, 857–858
Respiratory demand, 218–219. *See also* Breathing
Respiratory depression, 122
Respiratory distress. *See* Dyspnea
Respiratory Distress Observation Scale (RDOS), 220, 372–373, 373*t*, 581*f*, 629
Respiratory system, dying process and, 356
Respiratory therapy, 94*c*
Restlessness. *See* Agitation and restlessness
Restraints, 325
Resuscitation efforts, 41–42. *See also* Do Not Resuscitate orders (DNR)
  effectiveness of, 827–828
  family presence during, 633
Retching, 150. *See also* Nausea and vomiting
Rheumatoid arthritis (RA), 134
Rhodes and McDaniel, 153, 153*b*
Richmond Agitation-Sedation Scale (RASS), 627
Right-to-die, 838. *See also* Assisted dying
Rigor mortis, 428
Risk Evaluation Management Strategy (REMS), 196
Rituals, 425–427, 452
  cultural considerations in, 479–480
  grief and, 768
  soul injury, 542
Robert Wood Johnson Foundation (RWJF), 620, 849
Rogers v. Commissioner of Department of Mental Health, 510
Royal Victoria Hospital (Montreal), 15
Rural palliative care, 670–678
  academic-community partnerships in, 677–678
  barriers and challenges in, 672–673
  case studies, 670*c*
  clinical and research implications, 678
  clinical capacity development, 676
  Critical Access Hospitals, 677
  definition, 672*b*
  international, 673
  lay health workers in, 676–677
  telemedicine and telehealth, 617, 673–675
Rush Spiritual Screening Protocol, 37, 435

Safety, delirium and, 325
Safety net providers, 492
Saliva production, 176, 703. *See also* Sialorrhea (excess oral secretions); Xerostomia (dry mouth)
SAMe, 366
Satisfaction with care
  in intensive care units, 633
  measurement of, 582–584
Saunders, Cicely, 844
SCALE (Skin changes at life's end), 254, 254*t*
Schizoid personality disorder, 508
Schizophrenia, 321, 504–506
Schizotypal personality disorder, 508
Schools, pediatric palliative care and, 718
Scientific Registry of Transplant Recipients, 546
Scopolamine, 156
Scotland, 6
Screener and Opioid Assessment for Patients with Pain (SOAPP), 523
Secondary losses, 784
Secondary palliative care, 17
Secondary traumatic stress symptoms, 819
Secretions. *See* Sialorrhea (excess oral secretions); Terminal secretions
Sedation. *See* Palliative sedation
Sedation Agitation Scale (SAS), 627
Seizures, 291–293
  in children, 705, 781
  definition, 294*t*
  safety guidelines for, 294*b*
Selective serotonin reuptake inhibitors (SSRIs), 191, 313–314, 325
Self-awareness, 32, 33*b*
Self-care, 248, 684–685, 817–822, 835
Self-care planning, 821
Self-determination, 327, 357, 621, 834. *See also* Autonomy; Patient Self-Determination Act of 1990
Self-efficacy, 821
Self-expanding metallic stents (SEMS), 662
Self-management techniques, 316
Self-reflection, 821
Senior communities, 616
Seniors. *See* Older adults
Sensitivity, 62. *See also* Cultural competence
Sensory deficits, 273–274
Sensory loss, spinal cord compression and, 349
Sequential circumference arm measurements, 242–243, 243*f*
Serious Illness Care Program, 83
Serious Illness Project, 9
Serotonin Type 4 receptor antagonists, 191
Serotonin-norepinephrine reuptake inhibitors, 313
Service-learning projects, 18
Severe and persistent mental illness (SMPI), 503–511. *See also* Anxiety; Depression; Mental illness; Mood disorders; Psychotic disorders
  advance directives and, 510
  aggression and, 510–511
  barriers to care, 503–504
  bipolar and related disorders, 506–507
  capacity and competency determinations, 510
  case studies, 506*c*, 507*c*, 509–510*c*
  communication issues and, 505–509, 511
  definition, 504
  ethical considerations and, 510–511
  family issues and, 511
  nonpharmacological management, 505, 507
  personality disorders, 508–510
  pharmacological management, 504–507, 510
  prevalence of, 503
  research on palliative care and, 503–504
  schizophrenia and psychotic disorders, 504–506
  substance use disorders and, 525
Sexual dysfunction, medication classes associated with, 338*t*
Sexual orientation. *See* LGBTQIA (lesbian, gay, bisexual, transgender, queer/questioning, intersex, and asexual) populations
Sexuality, 337–342
  body image and, 338–339
  case studies, 337*c*–339*c*
  definition, 337
  diseases and, 340*t*
SF-MPQ-2 (Short Form-McGill Pain Questionnaire-2), 108
SGA (Subjective Global Assessment for Nutrition), 143
Shared decision-making (SDM), 738–739
Sharing narratives, among healthcare professionals, 634
Shewhart Cycle. *See* FOCUS-PDSA model
Shinto mourners, 392
Short Form McGill Pain Questionnaire (SF-MPQ), 108
Shortness of breath. *See* Dyspnea
Shortness of Breath with Daily Activities Questionnaire (SOBDA), 220
Shunts, 202
Sialorrhea (excess oral secretions), 163, 176–178
  assessment, 177
  in children, 703
  definition, 176
  etiology, 177
  incidence, 177
  management, 177–178
Sialorrhea Scoring Scale (SSS), 177*b*
Siblings. *See also* Families
  grief of, 761–762, 767
  support for, 718

Singultus. *See* Hiccups
Six Sigma 7-Step Problem-Solving Method, 574
Six Sigma Health Care Benchmarking Association, 581
Skilled nursing facilities, 607, 616. *See also* Nursing homes
Skin care and management
  lymphedema and, 249, 258
  periwound, 257*t*
Skin disorders. *See* Fistulas; Malignant fungating wounds (MFW); Pressure ulcers; Stomas; Wound, ostomy, and continence (WOC) care
Skin failure, 254
Skin Tear Audit Research (STAR) classification system, 262
Skin tears, 262–266, 267*t*
Skirted telling, 785
Sleep disorders
  complementary and integrative therapies for, 365–366
  cough and, 224
  fatigue and, 136
  insomnia, 330–335
Sleep-wake disturbances, 326
SMPI. *See* Severe and persistent mental illness
SNAP (Spiritual Needs Assessment for Patients), 435
SOAP (Subjective, Objective, Assessment, Plan) notes, 443
Social Capital Theory, 791–792
Social justice, 500
Social media, 64, 786, 791–797
  categories of, 792*t*
  ethical considerations, 797
  family communication and, 795
  healthcare providers and, 796–797
  illness blogs on, 793–796
  leaving a legacy through, 463, 796
  professional networking and, 804
Social support, HIV and, 517
Social well-being, of older adults, 486
Social workers, 91, 93
Society of Critical Care Medicine, 625, 633, 833
Society of Palliative Pharmacists, 9
Society of Pediatric Nursing, 724
Socioeconomic status, 490–500
  cultural influences on, 476 (*See also* Poor populations)
  vulnerability and, 490
Somatostatin analogues, 156, 195
Sonata (zaleplon), 335
Soul, dark night of, 459
Soul injury, 534*b*, 541–542
South Carolina, 678
Space, 879
Spanish Transplant Organization, Organización Nacional de Trasplantes (ONT), 545
Spasticity, 295–297
Specialty palliative care, 7, 849
Speech language pathology (SLP), 94*c*, 168–169, 682–688
SPIKES model for communication, 62
Spinal cord compression (SCC), 348–349
SPIRIT assessment model, 436*t*
Spiritual AIM (Assessment and Intervention Model), 438–439
Spiritual assessment, 432–444
  during active dying, 50–53
  after treatment, 49
  cancer survivorship and, 535
  of children, 442
  conducting, methods for, 439–441
  data interpretation and documentation, 443–444
  at diagnosis, 45–46, 46*c*
  dignity therapy for, 439
  diversity and, 443
  of family caregivers, 442–443
  history-taking, 435–437
  of impaired patients, 441–442
  importance of, 432–433
  language considerations in, 440
  listening skills in, 441
  models for, 433–439
  of nonverbal indicators, 440
  organizational approaches to, 444
  rapport in, 440
  screening, 37*b*, 434–435
  timing of, 439–441
  during treatment, 47–48
Spiritual care, 447–453
  case studies, 447*c*, 453*c*
  chaplain referrals in, 448*b*
  chaplains and, 90–91
  compassion, 449–450
  compassionate presence and deep listening in, 450
  conscious dying and, 452–453
  definition, 447
  elements of, 448–449
  hope in the dying and, 386
  love and, 453
  modalities, 451–452
  questions in, 448*b*
  rituals and, 452
  spiritual well-being, 447
Spiritual history, 435–437
Spiritual screening, 37*b*, 434–435
Spiritual suffering, 106
Spirituality. *See also* Religion; Spiritual assessment; Spiritual care
  of adolescents, 786–788
  anorexia and, 142
  in children, 706
  cultural influences on, 475
  definition, 36, 432, 447
  HIV/AIDS and, 516–517
  of older adults, 486
  palliative sedation and, 357
Spouses. *See* Caregivers; Families
St. John's Wort, 366
Standards for Clinical Education of Hospice and Palliative Nurses (HPNA), 10
State policy and regulations, 29, 620, 801
State-Trait Anxiety Inventory (STAI), 311
Status epilepticus, 291
Steroids, 195, 324
Stillbirth, 401, 753–755, 761
Stimulant laxatives, 190
Stoicism, 104–105, 539, 540, 543
Stomas, 272–273, 272*b*, 273*t*, 274*t*
Store-and-Forward telehealth technology, 674*b*
Storytelling, 793
Stress. *See also* Occupational stress
  biological systems and, 817–818
  correlation with morbidity, 48
Stridor, 631
Subcultures, 469
Subjective Global Assessment for Nutrition (SGA), 143
Substance p antagonists, 156–157
Substance use disorders (SUD), 521–528. *See also* Addiction
  12-step programs and, 527
  advanced diseases and, 523–528
  assessment of, 523–525
  case studies, 524*c*
  clinical management, 525–526
  family sessions and meetings, 527
  homelessness and, 492, 496*c*
  outpatient palliative care and, 646–647
  pain assessment and, 106–107
  psychiatric disorders and, 506, 527
  relapse prevention, 525–527
  risk factors for, 526
  terminology, 522*t*
  therapeutic goals for, 527
  withdrawal symptoms, 527
Subtle Energy Realms (SERs), 452–453
Suffering. *See also* Pain
  assisted dying and, 839–841
  of caregivers, 762
  existential, 357–358, 705–706, 840
  hope and, 379
  meaning and, 457–458
  palliative sedation and, 356–359
  spiritual, 106
Suicide and suicidal ideation. *See also* Assisted dying; Physician-assisted suicide (PAS)
  mental illness and, 505–508
  screening for, 47
Superior vena cava obstruction (SVCO), 344–345
Support, social media and, 792–796
SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments), 573
Supportive services
  for bereavement, 396–399
  definition, 737*b*
  for neonatal palliative care, 753
Surfactant/detergent laxatives, 189–190
Surgical interventions. *See* Palliative surgery
Surprise questions, 23
Surrogate decision-makers, 66–67, 828–829. *See also* Durable power of attorney for healthcare (DPOA)
  delirium and, 327
  family caregivers as, 415–417
  naming of, 81–82*c*, 82
  parents as, 737
Survivors. *See also* Cancer survivorship
  definition, 48
Suvorexant, 335
Swallowing. *See also* Dysphagia
  clinical examination of, 168
  compensatory strategies for, 169–171
  instrumental evaluation, 169, 170*t*
  physiology of, 163–165, 164*f*
  screening of, 168–169
Sweats and hot flashes, 289–290
  case studies, 289*c*
Switzerland, 838
Symptom assessment and management. See also *specific symptoms and conditions*
  cultural considerations in, 479
  in intensive care units, 624
Symptom clusters, 219
Symptom Distress Scale, 135
Systematic desensitization, 159
Systems assessment, 22
Systems perspective, on spirituality, 36

Talk therapy, 314–315, 397
Tapentadol, 121–122

Task level of communication, 56
Taste alterations, 163, 179–182
TB-TTI (Trombley-Brennan terminal tissue injuries), 254
Teach-back, 316
TEAM approach, 692
Team meetings, 23
Teamwork. *See also* Interdisciplinary teams (IDT)
  communication and, 72–75
“Teas for the Soul” program, 463
Technical evidence panels (TEPs), 573
Teenagers. *See* Adolescents; Children and adolescents
Teleconferences, 26
Telehealth, 673–675
Telephone support, in outpatient palliative care, 644
Tenderness, 450
Terminal anguish, 357–358
Terminal dehydration, 424
Terminal extubation, 373
Terminal restlessness, 631
Terminal secretions, 217, 225–226. *See also* Death rattle
  assessment/measurement, 225
  management, 225–226
Terminal sedation. *See* Palliative sedation
Terminal weaning, 373, 630, 631*t*
Tertiary palliative care, 17
Testing. *See* Assessment; *specific assessment measures*
Thalidomide, 145, 224
Theory of Self-Transcendence, 448
Therapeutic paracentesis, 202
Therapeutic Touch, 366
Thirst, 210, 629. *See also* Dehydration; Drinking; Hydration; Medically administered nutrition and hydration
Thoracentesis, 346, 347
Thrombolytic therapies, 345
Thrombosis, 241–242*c*
TIME (wound bed preparation), 258*b*
Time orientation, 382
TJC. *See* The Joint Commission
Toileting, 233, 234*t*
Total pain, 103, 256, 256*b*, 269, 840
Total parenteral nutrition (TPN), 193–194, 279, 663
Touch, 462
Tracers, for quality improvement, 583–585
Tracheostomy, 371, 373
Traditional Chinese medicine (TCM), 363, 364
Traditional healers, 363
Tramadol, 121–122
Transactional communication, 863
Transcendence, 461–462
Transdermal fentanyl, 120, 196
Transgender populations, 475, 499*c*. *See also* LGBTQIA (lesbian, gay, bisexual, transgender, queer/questioning, intersex, and asexual) populations
Transition of fading away, 406–412. *See also* Family-centered palliative care
Transitions of care, 27
Translator services, for patients and families, 37–38
Transmucosal immediate-release fentanyl (TIRF), 120–121
Transpersonal development, 450–451
Transpersonal nurse coaching (TNC), 450–451
Trazodone, 335
Treatment
  assessment after, 48–49
  assessment during, 46–48
  decision-making by parents for children, 736
  pain assessment and, 113
Trigger tools, for consultations, 23, 24–25
Tropisetron, 155
Trustworthiness, 878
Truth-telling, 382, 878
  cultural considerations and, 479
  in parent-child communication, 784–786
Tumblr, 791
Tumors, 165–166, 187. *See also* Cancer
Twitter, 791–793
  health information on, 794–795
Two-world model, of adolescents, 786

UCSD Shortness of Breath Questionnaire, 220
UI. *See* Urinary incontinence
Ultrasound, 346
Unbounded, state of being, 268
Uncertainty, 728–734
Uncomplicated grief, 394
Underserved populations, 490–500. *See also* Poor populations
Uniform Anatomical Gift Act (UAGA), 545
Uniform Donor Card, 545
United Network for Organ Sharing (UNOS), 545–546
United States (U.S.)
  aging in, 483
  assisted dying in, 838–839
  diversity in, 469–470, 483
  healthcare expenditures, 690
  healthcare system, 848–849
  organ donation regulations, 545–546
  quality improvement in, 573–574
  rural palliative care, 670–678
University of Alabama at Birmingham (UAB) Health System Cancer Community Network (CCN), 676
University of Colorado, 620
University of Maryland, 620
Unresolved grief, 395
Untimely death, grief and, 400
Upper motor neurons, 295
Urban poor, 496–497. *See also* Poor populations
Uremic pruritus (UP), 286–287
Urgent end of life syndromes, 344–353
  bone metastasis and pathological fractures, 352–353
  hemoptysis, 347–348, 349*t*
  hypercalcemia, 350–352
  pleural effusion, 345–347
  spinal cord compression, 349–350
  superior vena cava obstruction, 344–345
Urinary dysfunction, 230–236
Urinary incontinence (UI)
  dermatitis resulting from, 279–280
  management, 233, 235
  stomas and, 272–273, 273*t*
Urinary tract infections (UTI), 230, 235

Vacco v. Quill, 211
VADs. *See* Left ventricular assist devices (LVADs)
Valerian root, 366
Value-based care, 690–693
  pediatric goals of care and, 733
  reimbursement and, 619
Ventilation. *See* Mechanical ventilation (MV)
Ventilatory capacity, 219
Verbal Descriptor Scale (VDS), 107, 109*t*
Vermont, 837
Vertical pain thermometer (VPT), 107, 109*t*
Veterans, 539–544
  bereavement care for, 543–544
  case studies, 542*c*
  culture of combat and, 539–540
  environments of comfort for, 540–541
  honoring, 542
  moral injury, 541–542
  post-traumatic stress disorder among, 540–544
  resources for, 541*b*
  soul injury, 541–542
  stoicism of, 539–540, 543
Veterans Affairs (VA), U.S., 89, 539, 583, 607
Veterans Health Administration, 675
Victoria Respiratory Congestion Scale (VRCS), 225
Viral enterocolitis, 196
Vision deficits, 275
Visual Analog Scale (VAS), 107, 109*t*, 135, 142, 220, 224
Visualization techniques. *See* Guided imagery
Vital signs, 423
Vital Talk, 9, 83
Vitamin D, 365
Vlogging, 463
Vocalics, 56
Voiding dysfunction, 231–233
Volume depletion, 208
Voluntary stopping of eating and drinking (VSED), 834, 841
Volunteers, 91–94*c*
Vomiting. *See* Nausea and vomiting
Vulnerable populations, defined, 490. *See also* Homeless populations; Poor populations

Wald, Florence, 844
War, culture of, 539–540
Wartime bereavement, 391
Washington, 837
Water displacement, 243
Web technology. *See also* Internet; Online resources
  communication and, 64, 317, 786
  telehealth, 673–675
Well-being, 820
Wellness plan, 820*b*
White populations, 469, 470*t*
  medically administered nutrition and hydration use among, 213
  pain management, 479, 525
  poverty among, 491
WHO. *See* World Health Organization
Whole healing traditions, 362–363
WILDA pain assessment tool, 101–103, 102*t*, 107–108*f*
Wills. *See* Advance care planning (ACP); Living wills
Withdrawal of life-sustaining treatments, 423–425, 567, 626, 629–631, 632*t*, 737*b*, 829–834, 830*c*, 840
WOC. *See* Wound, ostomy, and continence (WOC) care
Wong-Baker FACES pain scale, 107, 109*t*
Word anchors, 107
Workplace. *See* Occupational stress
World Health Organization (WHO)

- organ donation data, 545
- on palliative care, 405, 433, 691, 870*b*
- palliative care and, 755
- palliative care as defined by, 573

Wound, ostomy, and continence (WOC) care, 251–280. *See also* Fecal incontinence; Malignant fungating wounds (MFW); Pressure injury (PI); Urinary incontinence (UI)
- advanced symptoms in complex and nonhealing wounds, 255–258
- assessment, 258–259, 262*b*
- case studies, 252–253*c*, 279*c*
- infection control, 256
- management, 252–253*c*, 252–271, 253*b*, 255*f*, 266
- nursing roles, 252, 252*b*

Wound, Ostomy, Continence Nurses Society (WOCN Society), 254

Xerostomia (dry mouth), 163, 178–179, 424
- assessment, 178–179, 178*b*, 179*b*
- definition, 178
- dehydration and, 210
- etiology, 178
- in intensive care units, 629
- management, 179, 179*b*, 180*t*, 629
- prevalence of, 178

X-rays, 346

Yoga, 365, 462

Young adults, 474
- HIV transmission among, 513
- sexuality and intimacy, 340–341

Youth. *See* Children and adolescents

YouTube, 791

Zaleplon (Sonata), 335

Zolpidem (Ambien), 335