

Surgical Palliative Care: *A Resident's Guide*



Geoffrey P. Dunn, MD, FACS | *Editor-in-Chief*
Robert Martensen, MD, PhD | *Associate Editor*
David Weissman, MD, FACP | *Associate Editor*



Surgical Palliative Care: *A Resident's Guide*

Geoffrey P. Dunn, MD, FACS | *Editor-in-Chief*

Robert Martensen, MD, PhD | *Associate Editor*

David Weissman, MD, FACP | *Associate Editor*

Surgical Palliative Care: A Resident's Guide is intended as an educational tool to assist surgeons and surgical residents in improving the end-of-life care for surgical patients and to help them address difficult issues with those patients and their families. The authors are responsible for the content and completeness of the material in this book and do not necessarily represent the policy of their employers, the American College of Surgeons, or the Cunniff-Dixon Foundation. The American College of Surgeons and the Cunniff-Dixon Foundation cannot accept, and expressly disclaim, liability for claims arising from the use of this work.

© 2009 American College of Surgeons
633 N. Saint Clair St.
Chicago, IL 60611-3211

Cunniff-Dixon Foundation
PO Box 800
Essex, CT 06426

All rights reserved.

Table of Contents

Statement of Principles of Palliative Care.....	v
Foreward.....	vii
Editorial Board.....	ix
Preface.....	xi
Introduction.....	xiii
CHAPTER 1 Personal Awareness, Self-Care, and the Surgeon-Patient Relationship.....	1
CHAPTER 2 Pain.....	17
CHAPTER 3 Dyspnea.....	43
CHAPTER 4 Delirium.....	53
CHAPTER 5 Depression.....	63
CHAPTER 6 Nausea.....	73
CHAPTER 7 Constipation.....	83
CHAPTER 8 Malignant Bowel Obstruction.....	93
CHAPTER 9 Cachexia, Anorexia, Asthenia, Fatigue (Wasting Syndromes).....	105
CHAPTER 10 Artificial Hydration and Nutrition.....	113
CHAPTER 11 Selected Symptoms.....	121
CHAPTER 12 Palliative Surgery: Definition, Principles, Outcomes Assessment.....	131
CHAPTER 13 Pediatric Palliative Care.....	141
CHAPTER 14 Cross-Cultural Encounters.....	163
CHAPTER 15 Delivering Bad News.....	179
CHAPTER 16 Goals of Care/Conducting a Family Conference.....	191
CHAPTER 17 The DNR Discussion.....	203
CHAPTER 18 Palliative and Hospice Care and Referrals.....	213
CHAPTER 19 Care during the Final Days of Life.....	227
CHAPTER 20 Discussing Spiritual Issues—Maintaining Hope.....	241
Index.....	253



Statement of Principles of Palliative Care

The following statement was developed by the Task Force on Surgical Palliative Care and the Committee on Ethics, and was approved by the Board of Regents at its February 2005 meeting.

Palliative care aims to relieve physical pain and psychological, social, and spiritual suffering while supporting the patient's treatment goals and respecting the patient's racial, ethnic, religious, and cultural values. Like all good patient care, palliative care is based on the fundamental ethical principles of autonomy, beneficence, nonmaleficence, justice, and duty.

Although palliative care includes hospice care and care near the time of death, it also embraces the management of pain and suffering in medical and surgical conditions throughout life. If palliation is taken to apply solely to care near the time of death, or "comfort measures only," it fails to include the life-affirming quality of active, symptomatic efforts to relieve the pain and suffering of individuals with chronic illness and injury. In this respect, palliative care is required in the management of a broad range of surgical patients and is not restricted to those at the end of life.

The tradition and heritage of surgery emphasize that the control of suffering is of equal importance to the cure of disease. Moreover, by adhering to the standards of professionalism endorsed by the American College of Surgeons, the surgeon is positioned to take a leadership role in advocating for palliative care for all patients.

The Statement of Principles of Palliative Care is an evolutionary step beyond the American College of Surgeons' 1998 Statement of Principles Guiding Care at the End of Life. It describes extending palliative care to a broad range of patients receiving surgical care.

Statement of principles of palliative care

1. Respect the dignity and autonomy of patients, patients' surrogates, and caregivers.
2. Honor the right of the competent patient or surrogate to choose among treatments, including those that may or may not prolong life.
3. Communicate effectively and empathically with patients, their families, and caregivers.
4. Identify the primary goals of care from the patient's perspective, and address how the surgeon's care can achieve the patient's objectives.
5. Strive to alleviate pain and other burdensome physical and nonphysical symptoms.
6. Recognize, assess, discuss, and offer access to services for psychological, social, and spiritual issues.
7. Provide access to therapeutic support, encompassing the spectrum from life-prolonging treatments through hospice care, when they can realistically be expected to improve the quality of life as perceived by the patient.
8. Recognize the physician's responsibility to discourage treatments that are unlikely to achieve the patient's goals, and encourage patients and families to consider hospice care when the prognosis for survival is likely to be less than a half-year.
9. Arrange for continuity of care by the patient's primary and/or specialist physician, alleviating the sense of abandonment patients may feel when "curative" therapies are no longer useful.
10. Maintain a collegial and supportive attitude toward others entrusted with care of the patient.

Reprinted from *Bulletin of the American College of Surgeons* Vol. 90, No. 8, August 2005



Foreword

I founded the Cunniff-Dixon Foundation in 2005 to honor my late wife—Carley Cunniff—and the care she received from Peter Dixon, MD, a physician who practices oncology in Lyme, CT. Carley, who was well-regarded on Wall Street for her acumen as an investment analyst and manager, discovered a small lump on her right breast in June of 2001, when she was 51. Learning that it was malignant, she promptly underwent surgery—a lumpectomy and subsequent mastectomy—at Memorial Sloan Kettering, where she volunteered on a board for many years. Four months later she learned the disease was metastatic, at which point she received hormone suppressant therapy. In 2002 we acquired an old farm house on beautiful land in Connecticut. While we talked often about the probable outcome of her disease, she never lost her spirit or her engagement with her friends and the world around her. Between 2002 and late 2004, when we learned the disease had invaded her central nervous system, Carley spent increasing amounts of time outside, working in her gardens and turning our new home into a beautiful retreat. During Carley’s final year, Peter took wonderful care of Carley and became a trusted friend and advisor to me and to Carley’s family. He would frequently come to the house after his last hospital rounds, spend time with Carley upstairs, and then join the rest of us in the kitchen for a brief dinner. Peter’s presence reassured us, his skillful palliative care aided Carley with her symptoms, and his advice made our decisions easier. Because of Peter, Carley was able to die peacefully and comfortably at home in January 2005 in the company of those closest to her.

During the next year I explored what to do with the Cunniff-Dixon Foundation, which I had created shortly after Carley’s death. As I talked with friends and medical professionals, it became clear to me that the end-of-life experience which Carley and I had been privileged to experience was all too rare in the world of modern medicine. I also learned that major progress was being made in palliative care, hospice care, and in the social work community. But it became my view that not enough attention was being paid to the education and inspiration of individual physicians concerning how to care for patients living with life-limiting diagnoses. I decided to try to do something about that.

Cunniff-Dixon’s mission is to educate and inspire physicians regarding medical care near and at the end of patients’ lives. Our resources are not substantial enough to address many of the institutional problems and issues that hold back better end-of-life care, and there are professional groups and individuals who are better equipped to take on those issues. But Cunniff-Dixon can make a difference with individual doctors, one doctor at a time. And we care deeply about that and believe that over five or 10 years we can influence clinical behavior in a way that will enable thousands more patients and patients’ families to have the experience they deserve and that Carley and I were blessed to have.

Cunniff-Dixon is proud and grateful to have the opportunity to work with the American College of Surgeons on this important curriculum project. It will result in expanded training and motivation in end-of-life medical care among the surgical community. Surgeons are frequently the people to whom patients and their families look for ultimate answers and guidance. It is important that surgical residents learn to be comfortable with that responsibility and that they care deeply about staying with their patients near the end of life. If this curriculum project helps to achieve that, I believe that we will have made an important difference.

—Andy Baxter



Editorial Advisory Board

EDITOR-IN-CHIEF

Geoffrey Dunn, MD, FACS

Chair
Surgical Palliative Care Task Force
American College of Surgeons
Chicago, IL

ASSOCIATE EDITOR

Robert Martensen, MD, PhD

Senior Advisor, Cunniff-Dixon Foundation
Essex, CT

ASSOCIATE EDITOR

David Weissman, MD

Director, Palliative Medicine Program
Professor of Medicine
Medical College of Wisconsin
Milwaukee, WI

CONTRIBUTING AUTHORS

Ciarán T. Bradley, MD, MA.

Resident in Surgery
Department of General Surgery
Medical College of Wisconsin
Milwaukee, WI

Karen J. Brasel, MD, MPH, FACS

Professor of Surgery (Trauma and Critical Care)
Medical College of Wisconsin
Milwaukee, WI

Elizabeth H. Castillo, MD, PhD

Director
Geriatrics Fellowship Program
MAHEC Family Health Center
Asheville, NC.

Thomas R. Cole, PhD

Professor and Director
McGovern Center for Health, Humanities,
and the Human Spirit
University of Texas Health Science Center
Houston, TX.

Kenneth Deville, JD, PhD

Professor of Medical Humanities
Brody School of Medicine
Greenville, NC.

Peter Dixon, MD

Specialist in Hematology and Oncology
Essex, CT

Daniel B Hinshaw, MD, FACS

Professor of Surgery (Section of General Surgery)
University of Michigan School of Medicine
Ann Arbor, MI

Sharon R. Kaufman, PhD

Professor of Medical Anthropology
University of California
San Francisco, CA

Jeffrey C. Klick, MD

Director of Education
Pediatric Advanced Care Team and Palliative Care Fellowship
Children's Hospital of Philadelphia
Philadelphia, PA

Thomas Murray, PhD

President
The Hastings Center
Garrison, NY

PROJECT ADVISERS

Andy Baxter

Founder
The Cunniff-Dixon Foundation
Lyme, CT

Linn Meyer

Director
Division of Integrated Communications
American College of Surgeons
Chicago, IL

Thomas R. Russell, MD, FACS

Executive Director
American College of Surgeons
Chicago, IL

Ajit K. Sachdeva, MD, FACS, FRCS

Director
Division of Education
American College of Surgeons
Chicago, IL

Insight

After we die we hover for a while
at treetop level with the mourners
beneath us, but we are not separate
from them nor they from us.
They are singing but the words
don't mean anything in our new language.

—Jim Harrison, *In Search of Small Gods*
Port Townsend, WA: Copper Canyon Press, 2009

Preface: The Case for Palliative Care

When Surgeon Balfour Mount, MD, coined the term “palliative care” in 1975, he wanted surgeons to assess possible interventions for patients with life-limiting diagnoses in terms of their impact on patients’ overall quality of life, not just their capacity to survive the first 30 postoperative days or a prolonged stay in an ICU. He believed that surgeons and their patients (and families) should jointly consider how to manage the patient’s illness. His goal, which is the goal of palliative care, was to anticipate, prevent, and treat the suffering patients experienced in the late phases of a life-threatening disease or condition. Weighing the potential impact of any intervention on longevity—the traditional criterion of effectiveness—was part of the picture, but he and others thought that comfort and function deserved equal consideration. And he wanted surgeons to engage with patients with life-threatening diagnoses sooner rather than later in their illness trajectories. As physician Eric Cassell noted in 1982, “The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians’ failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself.”¹

Until the late 1990s, hospice services were the health care system’s only response to Mount’s call for palliative approaches. Now hospice services are widely available for patients with a life expectancy of six months or less. In order for patients to receive the Medicare Hospice Benefit, however, they must renounce insurance coverage for curative or life prolonging treatment to be eligible. Adopting a palliative care approach makes no such demand. Palliative care has no prognostic requirement and does not insist that one choose between treatment approaches. Instead of emphasizing only treatments that may or may not extend life (or dying) without consideration of their impact on comfort or function, palliative approaches, of which hospice is a subset, seek a balance suitable for individual patients and their families. Achieving that balance often requires more than one doctor working with a patient, which is why palliative care by definition is an interdisciplinary undertaking of physicians, nurses, case managers, social workers, and chaplains.

Why is palliative care training necessary? When one looks at studies of what patients with life-threatening illness say they want and compares them to what patients actually experience, the gap is huge. Patients with late-stage illness say they want, in order of prominence (1) pain and symptom control, (2) to avoid inappropriate prolongation of the dying process, (3) to achieve a sense of control, (4) to relieve burdens on their families, and (5) to strengthen relationships with loved ones.²

What do patients experience? A well-done study of 9,000 patients with life-threatening illness revealed that half the patients experienced moderate to severe pain regularly, and more than 50% had severe pain during their last three days of life. Of those who died, 38% spent more than 10 days in an ICU, in coma, or on a ventilator.³ Fifty-three percent of Americans die in hospitals, 24% in nursing homes or skilled nursing facilities, and the remainder at home. In hospitals, inadequate management of pain remains a primary shortcoming. A study of 5,176 hospital patients revealed that even between days eight and 10—long after a patient should be familiar to providers—a majority of patients with colon and lung cancer, liver failure, and multisystem organ failure experienced moderate to severe pain. (ref: Desbiens & Wu. *JAGS* 2000;48:S183-186.)

As for caregivers, in 2006 Medicare estimated the U.S. contained 34 million persons who provided a mean of 21 hours per week to a seriously ill relative. (ref: Levine C. Loneliness of the long-term caregiver. *NEJM* 1999;340:1587-90. (Report to Congress: Medicare Payment policy Medpac, 2006.) A study of family caregivers revealed that most are women (61%) and most (60%) have other full-time jobs. A third of them are over age 65 and in poor health themselves. In providing care, a spouse faces substantial increase in mortality risk: for increased risk of MI, the RR is 1.8 if caring for an ill spouse more than nine hours per week,⁴ and in-home caregivers who report emotional strain experience an increased risk of death with an RR of 1.6 compared to controls.⁵ Family caregivers say they want the following, in order of prominence: (1) to have the patient’s wishes honored, (2) to be included in the decision process, (3) support at home; practical help in the form of transportation, medicines, equipment, (4) honest information and privacy, and (5) to be contacted after the death of the loved one.⁶ In assessing their satisfaction with hospital care of their relatives, 78% of family members report not enough contact with their relative’s physician, compared to 19% who reported their relative did not receive enough help with pain or SOB.

For patients, caregivers, AND physicians, the irony is that for patients in their final year, more medical care, meaning more procedures and prolonged ICU stays, leads to lower satisfaction with care. Family members of decedents in high-intensity hospital service areas report lower quality of emotional support, shared decision-making, information about what to expect, and respectful treatment. (ref: Teno et al. *JAGS* 2005;53:1905-11.) Physicians practicing in high health care intensity regions report more difficulty in: arranging elective admissions, obtaining specialty referrals, maintaining good doctor-patient relations, and delivering high quality care. (ref: Sirovich et al. *Annals Intern Med* 2006;44:642-649.) According to Dartmouth Health Atlas data, regions of highest spending (most specialist visits, hospital days, ICU use) have the highest mortality after risk

adjustment. (ref: ES Fisher et al. *JAMA* 2006;296:159-160. ES Fisher et al. *Health Affairs* 2004; suppl Web exclusive: VAR 19-32; ES Fisher et al. *Annals Intern Med* 2003;138:288-98.)

In its paper and Web versions, this *Resident Guide* provides basic knowledge and techniques of palliative care. In mastering them, you will learn how to be clear with patients, their families, colleagues, and yourself about the realities of a patient's disease picture and what your judgment and skill in the art of surgery can provide for their comfort, function, and longevity.

— Robert Martensen, MD, PhD

Endnotes

1. Eric Cassell, *NEJM* 1982;306:639-645.
2. Singer et al. *JAMA* 1999;281(2):163-168.
3. National Data on the Experience of Advanced Illness in 5 Tertiary Care Teaching Hospitals, *JAMA* 1995;274:1591-1598.
4. Lee et al. *Am J Prev Med* 2003;24:113.
5. Shultz et al. *JAMA* 1999;282:2215.
6. Tolle et al. Study of 475 family members 1-2 years after bereavement, Oregon report card.1999 www.ohsu.edu/ethics

Introduction

Surgeons will encounter many patients with progressive, incurable, and terminal illnesses in their role as primary physician or as a consultant. This manual has been written specifically for surgeons-in-training, regardless of their future sub-specialty career choices, to offer guidance for management of the salient problems encountered in palliative care, including advice on self-preparation and self-care necessary to execute these tasks competently while minimizing the risk of burn-out.

Surgical palliative care is interdisciplinary care whose goal is to relieve suffering and improve quality of life of the patient and his family dealing with a serious illness. It is by no means limited to patients in the final days to weeks of life. During the past decade the field of surgery has joined others recognizing palliative care as an essential component of patient care. For many surgeons this recognition was accelerated by favorable personal experience with patients and relatives who had received hospice care or by haunting memories of patients whose illness and death had none of the redeeming qualities of comfort, dignity, or meaning. This growing awareness by surgeons has occurred against the background of the public's increasing expectations of improved palliative care.

In addition to numerous studies documenting a pressing need for improved palliative care physician education, several studies by surgeons have led to recommendations for improved palliative care education for surgeons.

This book is a revision of *Palliative Care: A Resource Guide for Physician Education, 4th Edition* by David E. Weissman, MD, Bruce Ambuel, PhD, and James Hallenbeck, MD (2007). This curriculum has been used extensively for palliative care education in more than 400 residency programs, including general surgery, internal medicine, family practice and neurology. This current version has been revised specifically to meet the needs of residents in postgraduate surgical training. The selection of topics was based upon the experience of the authors in designing educational programs for medical students, postgraduate trainees and surgeons-in-practice. The book is not meant to be a comprehensive collection of palliative care teaching resources, rather, to highlight the topics of greatest educational need, as identified by surgical educators and surgical trainees.

Thomas R. Russell, Executive Director of the American College of Surgeons, pointed out in an editorial that the culture of surgery is changing, evolving along with long held values. He notes, “No longer is it “my” patient, but it is “our” patient.” This shared responsibility for the surgical patient is not without peril, though this ethic has a very positive application in the interdisciplinary model of palliative care. Although the focus of his remarks was directed at fundamental changes in residency training, his comments apply equally to the norms of surgical practice, especially palliative care: “We can start by building a sense of mutual respect for the broad range of individuals [including the patient and his family] involved in the care of our surgical patients, from nurses to allied health care professionals, from anesthesiologists to environmental service workers. As surgeons we must improve our communication and leadership skills, so these individuals will view us in a more positive light.” Surgical palliative care is an approach to patient care that can help us meet this challenge.

Surgeons have always been up to the unique challenges of their era. They have never disappointed those they serve in their degree of courage, practicality, and innovation; the changing landscape of illness and culture offer new opportunities for other insights and strengths to emerge. The authors wish that this manual will become an island of credibility for surgeons everywhere as they traverse the often stormy waters of life-limiting illness.

—Geoffrey P. Dunn, MD, FACS

—David E. Weissman, MD, FACP



CHAPTER 1

Personal Awareness, Self-Care, and the Surgeon-Patient Relationship

“Self-knowledge guides us in knowing when to give up on the hope of combating disease and when to soldier on; it prevents us from making decisions in which the real aim is to shore up our own personal defenses against insecurity; it shows us the sources of our own fears of death and lessens their acuteness; it puts our fears of passivity and impotence into perspective so that each failure of therapy is not the expense of reason. Most importantly, it enables us to fulfill our pastoral role as surgeons.

This, and not the technology, is what being a doctor is all about.”

—Nuland S. A surgeon’s reflections on the care of the dying. *Surg Onc Clin N Am.* 2001;10(1):1-5.

Learning Objectives

Attitudes

- Reflect on current self-care and personal awareness practices.
- Value the importance of personal awareness in caring for seriously ill patients and their families.
- Value the importance of personal care in preventing burnout.
- Reflect on the impact of patient care on personal and professional roles and responsibilities.

Knowledge

- Recognize how past professional and personal experiences can influence one's work with patients.
- Describe the basic steps in self-reflection.
- Describe the signs and symptoms of burnout.
- Describe strategies to avoid burnout.

Skills

- Practice self-reflection in the context of working with patients.
- Practice mutual support in the context of working with patients.

NOTES

Pre/Post Test

1. List two reasons why physicians may be fearful of exploring emotions of patients with life-threatening or advanced illness.

a. _____

b. _____

2. Name the three major components of personal awareness.

a. _____

b. _____

c. _____

3. Describe three strategies to avoid burnout.

a. _____

b. _____

c. _____

Answers

(1) fear of provoking painful emotions in (a) patient and (b) self, (2) awareness of self, patient, and environment, (3) take care of yourself through life balance, exercise, debrief painful events.

Humanizing Palliative Care for Patients and Surgeons

Caring for seriously ill or dying patients and their families presents unique personal and professional challenges to surgeons. In providing this care, surgeons confront their own mortality. Surgeons also confront the inevitability of their own personal losses through the loss experienced by patients' families. In addition, many surgeons have experienced a patient's death that is, for one reason or another, professionally difficult—making a death declaration for a patient one has never met before; facing the unexpected tragic death of a child or young person; caring for a patient who dies following an operation; caring for a patient who dies following an accident or assault. Standing with a patient and family as they confront death requires courage. Sustaining this courage over time requires personal awareness and attention to self-care.

Barriers to Effective Care of Patients Who Are Critically Ill or Dying

The need to improve palliative care is now well accepted by the health professions. Despite this acceptance, medical practice continues to lag behind. What are some of the barriers that surgeons and other health care providers encounter? Here is our list. If you present a workshop on self-care, you might ask your audience to brainstorm and generate its own list before presenting our list or your own list. Encourage participants to think beyond the more obvious training issues such as lack of knowledge and clinical skills.

1. Opening Pandora's box
 - Lack of knowledge and skill in caring for dying patients
 - Lack of confidence—What can I offer?
 - Lack of professional support—Modern medicine focuses on cure, but has not valued palliative care.
2. Past experience—Too close for comfort?
 - Negative, inactivating experiences with death and dying
 - Positive, enhancing, and enriching experiences with death and dying that were not affirmed and supported by peers
3. Fear of patient and family emotions
 - Anger, depression, anxiety, sadness, grief, lack of demonstrable emotion
4. Burnout—Surgery, is it an impairing profession?¹
 - Emotional burnout
 - Substance abuse
 - Lack of control over work environment
5. Spiritual challenge
 - Dealing with gravely ill patients can force one to confront spiritual questions—How can I offer spiritual care different from my beliefs? Should I?

Personal Awareness

What is personal awareness? Personal awareness involves insight into how one's sensations, emotional life, past experiences, thoughts, beliefs, attitudes, and values influence one's life experience, including interactions with patients, families, and other professionals.² Surgeon Sherwin Nuland³ wrote, "Self-knowledge guides us in knowing when to give up on the hope of combating disease and when to soldier on; it prevents us from making decisions in which the real aim is to shore up our own personal defenses against insecurity; it shows us the sources of our own fears of death and lessens their acuteness; it puts our fears of passivity and impotence into perspective so that each failure of therapy is not seen as a failure of one's self as a surgeon; it frees us of the need to burnish self-image at the expense of reason. Most importantly, it enables us to fulfill our pastoral role as surgeons. This, and not the technology, is what being a doctor is all about." Epstein⁴ talks about "mindful practice." "The goals of mindful practice are to become more aware of one's own mental processes, listen more attentively, become flexible, and recognize bias and judgments, and thereby act with principles and compassion. Mindful practice involves a sense of 'unfinishedness,' curiosity about the unknown and humility, having an imperfect understanding of another's suffering."⁴

Personal awareness includes three components: awareness of *self*, awareness of *the other*, and awareness of *the environment*.

1. **AWARENESS OF SELF**—Your sensations, emotions, thoughts, beliefs, attitudes, and values
 - **What do I believe?**
 - i. Are people good and trustworthy?
 - ii. Is my role as a surgeon a calling or a job?
 - iii. What are my cultural roots—ethnicity, gender, religion?
 - iv. What are my spiritual and religious beliefs—about death, about suffering, about what gives life meaning?
 - **Your experiences**
 - i. How did my family deal with death, emotion, and conflict?
 - ii. "How have my personal experiences with loss and grief affected, enhanced, or limited my abilities to work with dying patients? What are my own attitudes and fears of death and vulnerability, and how do they affect my patient care? If I were dying, what would I want and need from my physician?"²
 - **Your emotional life**
 - i. Affiliation: love, caring, attraction
 - a. What patients elicit feelings of caring? How do I usually respond to my own feelings of caring?
 - b. What patients elicit feelings of physical attraction? How do I usually respond to my own feelings of attraction?
 - c. How do I establish appropriate boundaries?

NOTES

- ii. Anger and conflict
 - a. “What sorts of patients elicit an angry reaction in me? What work situations usually make me angry and why? What are my usual responses to my own anger and the anger of others (e.g., do I overreact, placate, blame others, suppress my feelings, become super reasonable)? What are the underlying feelings when I become angry (e.g., feeling rejected, humiliated, and unworthy)? Where did I learn my responses to anger?”²
 - b. How do I establish appropriate boundaries?
2. AWARENESS OF THE OTHER, YOUR PATIENTS—Their sensations, emotions, thoughts, beliefs, attitudes, and values
- **Awareness of the patient’s illness experience⁵**
 The distinction between disease and illness reminds us that our medical understanding of a pathologic process is different from the individual patient’s understanding and experience of illness: Disease refers to a biologic, pathophysiologic understanding of the pathologic process, whereas illness refers to a patient’s experience of the process. The acronym, **FIFE**, guides us through an assessment of the patient’s experience of illness:
 - i. **F** = Feelings, especially specific fears and hopes. “Do you have any specific fears or concerns that I should know about? What hopes do you have?”
 - ii. **I** = Ideas about what is going on. “What do you think this pain (symptom) means?”
 - iii. **F** = Function: Impact on functioning. “How is your illness affecting daily activities? Are there things you want to do that you cannot do?”
 - iv. **E** = Expectations. What are your expectations... of the disease process; of your self; of others; of caretakers; of your physicians; of me?

- **Awareness of the patient as a whole person in the context of family and community⁵**
 - i. Where is the patient in the cycle of life (childhood, adolescence, young adulthood, parenthood, older adult)? (Is dementia present?)
 - ii. What has been important to the patient—for example, career, family, service in the community?
 - iii. What are the person’s spiritual beliefs and resources?
 - iv. Does the patient have unfinished personal business?
 - v. Who are the family and friends? What role have they fulfilled in the past, and what role are they fulfilling now?
 - vi. Where does the patient live? What are the physical surroundings like? Do the physical surroundings meet the patient’s needs now? Will this situation change as illness progresses?
 - vii. Does the patient belong to a religious community or other community organizations?
3. KNOW THE ENVIRONMENT
- What is the local professional environment regarding palliative care? What are my colleagues’ attitudes? What is the local skill level? In what ways will my work be supported or undermined?
 - Are there clinical systems in place to support my palliative care work? Do my hospital and clinic have resources for pain and symptom management? Are nurses well educated in palliative care? Do the quality assurance mechanisms include palliative care outcomes?

NOTES

The Pathway to Personal Awareness through Self-Reflection

Effective self-awareness requires a specific set of psychological and social skills that involve reflection on of one's own thoughts and feelings, awareness of others' thoughts and feelings, and the practice of acceptance and curiosity. The specific skills or tasks involved in self-reflection are described below.

1. Self-awareness of sensations, emotions, thoughts, and actions

Recognize and maintain awareness of your own sensations, emotions, thoughts, and actions when working with patients. One's sensations, thoughts, and feelings are often quite automatic. The interconnections among one's sensations, thoughts, feelings, and actions often go unnoticed.

2. Self-acceptance

- Accept your emotions, sensations, and thoughts openly, without judgment. These emotions, sensations, and thoughts are a natural part of your response to the world.
- Accept ownership of your emotions, sensations, and thoughts. These arise from your self; they are a part of you. They are not caused by anyone else. You alone are the source of your thoughts, sensations, and feelings.

3. Other awareness

Recognize and identify the emotions, sensations, and thoughts of your patients.

4. Other acceptance

Accept the patient's emotions and thoughts openly, without judgments. These emotions and thoughts are a natural part of the patient's response to the world.

5. Increase understanding by identifying cognitive and emotional schemata

- **Personal schemata:** By studying your automatic sensations, emotions, and cognitions over time, you can become aware of patterns—In what doctor-patient scenarios do you tend to feel angry? Happy? Depressed? Satisfied? Frustrated? Identifying personal schemata involves a process of sustained self-observation, curiosity, and hypothesis testing.
- **Other schemata:** By studying another's emotional and cognitive responses over time, you will become aware of patterns in their responses. In what scenarios do they tend to feel angry? Happy? Frustrated? Demoralized? Identifying another person's schemata also involves a process of sustained observation, curiosity, and hypothesis testing.

6. Increase understanding by identifying patterns of interaction over time

You do not live in isolation. You are always interacting with others. Your sensations, emotions, cognition, and behaviors influence others, and the emotions, cognition, and behaviors of others influence you. This process is constant and mutually reciprocal. You are linked with others in a constantly changing, dynamic web of interactions. The highest level of personal awareness involves awareness of your engagement in this web of interactions. How do your emotions, cognition, and behaviors influence the people around you? How do their emotions, cognition, and behaviors influence you? What patterns of interaction play out over time with a specific patient? As you explore interactions over time, you will be challenged to move from awareness to acceptance to understanding.

NOTES

Three Pathways to Self-Care

1. Balance personal and professional life

- What are my goals for work, play, family, community, and personal development?
- Am I achieving my goals in each domain? Where I am falling short? Can I accept responsibility for the choices I am making or do I feel like a victim? Can I move from a victim stance and instead set proactive goals?
- “What would be an ideal distribution of time between work, play, family, and personal growth and development? What are the barriers to achieving balance in my life? In what ways could my assumptions and beliefs be a barrier to change? In what ways is the current imbalance benefiting me and would I be willing to give that up?”²

2. Lead a healthy lifestyle

- Diet, exercise, and sleep
- Fun; social support
- Meaning, diverse goals, and optimism

3. Prevent burnout

- Stress occurs when there is a mismatch between the resources a person has available and the demands the person is facing. This mismatch includes internal psychological resources and demands, and external social and environmental resources and demands. Burnout results from chronic stress.

Know and Recognize the Signs and Symptoms of Burnout

- Emotional exhaustion: demoralization, irritability, withdrawal, depression, drug and alcohol abuse, marital conflict, family problems
- Depersonalization: feeling emotionally separated and numb, cynicism, erosion of empathy, hostility, control and manipulation of others
- Perceived professional inadequacy: loss of control, dissatisfaction with gains
- Substance abuse: use and abuse of controlled substances, illegal drugs, alcohol
- Social isolation and withdrawal: backing away from colleagues or family; immersing oneself in work to the exclusion of family and colleagues

NOTES

Factors that Increase Risk of Burnout

1. Irrational beliefs that promote excessive responsibility and place one at risk for burnout
 - Limitation in knowledge is a personal failing.
 - Responsibility is to be borne by physicians alone.
 - Altruistic devotion to work and denial of self are desirable.
 - It is “professional” to keep one’s uncertainties and emotions to oneself.
2. Tragic clinical situations
 - An untimely death: child, young adult, unexpected death, death due to an operative complication, death before an important future event
 - A patient suffering despite my best interventions
3. Surgical error
 - “What was the nature of my mistake? What are my beliefs about the mistake? What emotions did I experience in the aftermath of the mistake? How did I cope with the mistake? What changes did I make in my practice as a result of the mistake?”⁶
4. Abuse
 - Recognize abusive situations—Harassment and abuse based on sex, race, ethnicity, religion, sexual preference, or other factors is a significant source of distress and burnout in medical settings.
5. Lack of control
 - Over schedule
 - Over time
 - Over work environment

References

1. Krizek T. Ethics and philosophy lecture: surgery: is it an impairing profession? *J Am Coll Surg.* 2002;194(3):352–368.
2. Novack DH, Suchman AL, Clark W, et al. Calibrating the physician: personal awareness and effective patient care. *JAMA.* 1997;278(6):502–510.
3. Nuland S. A surgeon’s reflections on the care of the dying. *Surg Oncol Clin N Am.* 2001;10(1):1–5.
4. Epstein RM. Mindful practice. *JAMA.* 1999;282(9):833–839.
5. Stewart M, Brown JB, Weston WW, et al. *Patient Centered Medicine: Transforming the Clinical Method.* Thousand Oaks, CA: Sage Publications; 1995.
6. Levinson W, Dunn PM. Coping with fallibility. *JAMA.* 1989;261:2252.

NOTES

Bibliography

- Aoun H. From the eye of the storm, with the eyes of a physician. *Ann Intern Med.* 1992;116:335-338.
- Blust L. Fast Fact and Concepts #167: Health Professional Burnout: Part I. End of Life/Palliative Education Resource Center. Available at: http://www.eperc.mcw.edu/fastFact/ff_167.htm. Accessed July 23, 2009.
- Blust L. Fast Fact and Concepts #168: Health Professional Burnout: Part II. End of Life/Palliative Education Resource Center. Available at: http://www.eperc.mcw.edu/fastFact/ff_168.htm. Accessed July 23, 2009.
- Blust L. Fast Fact and Concepts #169: Health Professional Burnout: Part III. End of Life/Palliative Education Resource Center. Available at: http://www.eperc.mcw.edu/fastFact/ff_169.htm. Accessed July 23, 2009.
- Blust L. Fast Fact and Concepts #170: Health Professional Burnout: Part IV. End of Life/Palliative Education Resource Center. Available at: http://www.eperc.mcw.edu/fastFact/ff_170.htm. Accessed July 23, 2009.
- Bone RC. As I was dying: an examination of classic literature and dying. *Ann Intern Med.* 1996;124:1091-1093.
- Bone RC. The taste of lemonade on a summer afternoon. *JAMA.* 1995;273:518.
- Bone RC. Another “taste of lemonade.” *JAMA.* 1995;274:1656.
- Bone RC. Lemonade: the last refreshing taste. *JAMA.* 1996;276:1216.
- Butterfield PS. The stress of residency. *Arch Intern Med.* 1988;148:1428-1434.
- Eilers GM. I was a success at everything: except suicide. *Med Econ.* 1996; 29:105-109.
- Gabbard GO, Nadelson C. Professional boundaries in the physician-patient relationship. *JAMA.* 1995;273:1445-1449.
- Nuland SB. *How We Die: Reflections on Life's Final Chapter.* New York, NY: Alfred A Knopf; 1994.
- Pauwels JA, Benzer DG. The impaired health care professional. *J Fam Pract.* 1989;29:477-484.
- Richman JA, Flaherty JA, Rospenda KM, et al. Mental health consequences and correlates of reported medical student abuse. *JAMA.* 1992;267:692-694.
- Shapiro, J, Prislín MD, Larsen KM, et al. Working with the resident in difficulty. *Fam Med.* 1987;19(5):368-375.
- Wipf JE, Pinsky LE, Burke W. Turning interns into senior residents: preparing residents for their teaching and leadership roles. *Acad Med.* 1995;70:591-596.

Personal Awareness and Self-Care Teaching Workshop | Faculty Guide

1. Introduce self-care by talking about the ways in which caring for dying patients and their families can be personally and professionally rewarding, as well as demanding.
2. Share two or three examples from your own career. Ask others to share a rewarding or challenging experience.
3. Identify the gap between palliative care recommendations and actual practice (calls for greater use of opioids for pain versus reality—physicians fear of prescribing), then ask participants to brainstorm about why this gap exists. What are some of the barriers that physicians and other health care providers encounter (in addition to training issues such as knowledge and clinical skill)? Why do you think we haven't done a better job? (Write answers on blackboard, or use an overhead projector.)
4. Review the *Personal awareness* section of the outline.
5. Divide participants into groups of three or four. Hand out the “*Professional and Personal Experiences with Death and Dying*” worksheet, and ask each person to work through this alone in the next 5 to 10 minutes. Give a two-minute “warning,” and then ask the group to share their responses within their group (to the extent they are comfortable). After another 5 to 10 minutes, debrief the entire group by asking them what they learned by comparing their experiences with varied experiences of others. In what ways do their past personal and professional experiences enhance their work or present a challenge?
6. Review the *Pathways to self-care* section of the outline.
7. Talk about local resources for participants who are feeling burnout, anxiety, or depression.
8. You will want to prepare a resource sheet that lists appropriate local resource numbers, for example, the number for resident mental health services and/or employee assistance program, the office to contact in case of abuse or discrimination, and the hospital's physician impairment committee. Encourage participants to use these resources and to refer colleagues to these resources.
9. Give participants the handout titled “*Inventory of Personal and Professional Goals.*”
10. Ask participants to take 5 or 10 minutes to begin filling in this worksheet. As a large group or in smaller groups, ask people to reflect on their goals. Do they have diverse goals, or are they all in one category? Which goals are most important? Which goals are receiving the most time and energy? How are they doing at valuing and pursuing the goals that are most valued? Ask participants to take this handout with them and review their responses with a spouse or close friend. As an alternative activity, you can ask participants to complete this worksheet on their own time; discuss it with a spouse, family member, or close friend; and come prepared to discuss the worksheet at the next meeting.
11. As a follow-up to this module, faculty and residents should identify ways to continue a discussion of personal awareness and self-care in the residency. One approach to continue this dialogue is to devote several case conferences or discussion groups each year to talking about the challenges and rewards of palliative care. Another approach is to create a resident support group that focuses on personal awareness, self-care, and professional growth. Yet another approach is to build self-reflection into the daily work of caring for patients so that faculty and residents can discuss these issues while discussing patient care.

NOTES

Professional and Personal Experiences with Death and Dying: Discussion Worksheet

Our professional care of dying patients occurs in the context of our own history, including our personal and professional experiences with death and dying. Death is very personal. Please take a few minutes to respond the following questions. This page is for your own use—you will not be asked to hand in the notes you make. You will have a chance to share experiences during a small group discussion; however, please discuss only what you feel comfortable sharing. The goal of this experience is to facilitate our professional growth, not to conduct therapy.

1. Think about your first professional experience with the death of a patient. What was this experience like? How has this experience influenced your understanding and approach to caring for a dying patient and the patient's family?

2. Think about your first personal experience with death (such as friend, family member, relative, or pet). What was this experience like? How has this experience influenced your understanding and approach to caring for a dying patient and family?

3. In addition to these two experiences, have you had any professional or personal experiences with death that stand out as critical events that have influenced your understanding, empathy, and capacity to care for a dying patient and the patient's family?

4. In what ways do these past experiences represent a resource that you can draw on in working with dying patients? In what way do these experiences present challenges or barriers for you in working with dying patients?

Inventory of Personal and Professional Goals

Take the next 5 minutes to reflect on your personal and professional goals. Use the chart below to record your thoughts.

Individual goals
Spouse or significant other (If single, think about what your goals may be in the future)
Children
Social network: friends, church, clubs, organizations, and so forth
Professional

Faculty Strategies for Encouraging Personal Reflection Among Trainees

Strategy	Tactic
<p>Incorporate self-reflection into each case presentation.</p>	<ul style="list-style-type: none"> • Ask residents to comment on the doctor-patient relationship each time they present a case. See the outline, <i>A Patient-Centered Approach to the Medical History</i> for an example.
<p>Model self-reflection when working with residents.</p>	<ul style="list-style-type: none"> • Share your own emotional reactions. Reflect aloud with the treatment team about what was satisfying for you; what was emotionally challenging; what you might do next time to be more effective; what you have learned from working with this patient.
<p>Pose questions that prompt self-reflection when staffing palliative care patients with residents.</p>	<ul style="list-style-type: none"> • What is most challenging about working with this patient and family? • What is most satisfying about working with this patient and family? • How are you reacting emotionally to this patient? In what ways are you showing those feelings? • How did the patient benefit from working with you? How did the family benefit from working with you? • Have your past experiences in any way enhanced or hindered your work with this patient and family? • What gives this patient a sense of meaning and purpose? • Based on your work with this patient, what have you learned about yourself and about your strengths and weaknesses? What are your learning goals for the future?
<p>Ask residents to reflect on their work with each palliative care patient and respond in writing.</p>	<ul style="list-style-type: none"> • See the <i>Palliative Care Episode of Care Resident Education Documentation</i> page for one example of self-reflective questions.
<p>Create regular residency meetings to discuss the doctor-patient relationship.</p>	<ul style="list-style-type: none"> • Offer a resident support group or Balint group 2–4 times per month.
<p>Assign structured self-reflection during a palliative care rotation.</p>	<ul style="list-style-type: none"> • Read and discuss stories or novels that deal with death and dying. • Keep a written journal.



CHAPTER 2

Pain

“Divinum est sedare dolorem.” (Blessed are those who treat pain.)

—Galen

Learning Objectives

Attitudes

- Reflect on the personal meaning of pain and pain treatment.
- Understand that pain at the end of life can be effectively treated.
- Recognize that pain is best managed using a team approach to care.
- Understand that a complaint of “pain” may include physical, psychological, and spiritual dimensions.
- Understand that drug and nondrug treatments must be individualized for every patient.
- Understand that long-term opioid therapy is not synonymous with drug addiction.

Knowledge

- Identify at least two cultural barriers to pain management, such as the meaning of pain (punishment, benefit, redemptive value) and cultural values (stoicism, “no pain no gain”).
- Describe the differences and give examples of acute, chronic nonmalignant, and chronic malignant pain.
- Describe at least five medical barriers to pain management, for example, inappropriate linkage of prognosis with pain relief, fear of opioid side effects, fear of opioid tolerance, confusion between physical and psychological dependence, fear of regulatory agency scrutiny and sanction, and fear of ethical impropriety.
- Identify three patient and family barriers to pain management, for example, fear of disease progression, fear of drug side effects, fear of tolerance and addiction, and fear of morphine.
- Identify the neuroanatomic and clinical characteristics of the major types of pain: somatic, visceral, and neuropathic.
- Describe the World Health Organization three-step ladder for cancer pain relief. Identify at least one drug from each step, including indications, pharmacology, routes of administration, and side effects.

- Describe the indications, pharmacology, side effects, and costs of nonsteroidal anti-inflammatory drugs (NSAIDs) used for mild cancer pain.
- Describe the indications, pharmacology, side effects, and costs associated with morphine, hydromorphone, oxycodone, codeine, methadone, and fentanyl.
- Describe the indications, pharmacology, side effects, and relative costs of oral, transdermal, intravenous (IV), subcutaneous (SQ), intramuscular (IM), rectal, and sublingual routes of opioid administration.
- Identify the prophylactic and active treatment approaches to common opioid side effects: constipation, nausea, sedation, and confusion.
- Identify two patient- and two drug-specific risk factors for opioid-induced respiratory depression in a patient with pain.
- Define and distinguish opioid tolerance, physical dependence, and psychological dependence.
- Describe the indications, pharmacology, and side effects of one drug from each of the following adjuvant analgesic classes: tricyclic antidepressants, anticonvulsants, and corticosteroids.
- Describe the indications for the following psychological interventions: education, reframing, imagery, and progressive muscle relaxation.
- Describe patient cues that may signal psychological and/or spiritual pain.
- Describe consultation resources for pain problems that are difficult to manage.
- Identify federal and state regulations concerning prescribing practices for controlled substance.
- Explain the medical facts and ethical arguments concerning opioid-induced respiratory depression, physician-assisted suicide, and euthanasia in relation to opioid analgesics.
- Identify how to distinguish between patients taking opioids for pain from patients taking opioids because of psychological dependence.
- Describe the approach for treating pain in a patient with a terminal illness who is a current or former substance abuser.

NOTES

Skills

- Demonstrate communication and cognitive skills necessary to obtain a pain assessment for the following patients: adults, children, and patients with cognitive impairment.
- Construct a differential diagnosis for the cause of pain in three patients with cancer.
- Develop an initial and a long-term treatment plan for three patients with pain and cancer. The plan should include consideration of antineoplastic, drug, and nondrug therapies.
- Use skills of allied health care professionals in a collaborative effort to improve pain management.
- Demonstrate how to convert a patient's dose of oral opioids to a parenteral opioid analgesic while maintaining continuous analgesia.
- Prescribe strong opioids appropriately: dose titration orders, use of short-acting and/or long-acting opioids.
- Prescribe a tricyclic antidepressant and an anticonvulsant medication as an adjuvant analgesic appropriately, including dose titration.
- Demonstrate how to assist patients who have psychological or spiritual pain as a component of their pain experience.
- Counsel a patient and family in the use of pain medicines.
- Counsel a patient who is fearful of taking opioid analgesics.

NOTES

Pre/Post Test

- List one example of each major pain type:
 - somatic pain: _____
 - visceral pain: _____
 - neuropathic pain: _____
- When using opioid-nonopioid combination products, the suggested maximal daily dose of acetaminophen is: _____ g/d.
- When pain is poorly controlled, what percentage of the original dose is used to calculate a new higher dose?
 - For moderate to severe pain, escalate dose by _____%.
 - For mild to moderate pain, escalate dose by _____%.
- The fentanyl patch can be safely dose-escalated for uncontrolled pain no more frequently than every ____ hours.
- 10 mg of oral morphine is equianalgesic to:
 - _____ mg of oral hydromorphone (Dilaudid).
- Two common side effects of opioids that typically resolve within a few days owing to the development of drug tolerance include:
 - _____
 - _____
- List two characteristics that define psychological dependence (also called addiction and substance use disorder).
 - _____
 - _____

Answers

(1) Somatic: bone metastases; visceral: liver metastases with capsule distention; neuropathic: sciatica, (2) 3 g; (3) 50%–100% and 25%–50%, (4) 72 hours, (5) 2.5 mg, (6) sedation, nausea, (7) use despite harm, loss of control.

Pain Assessment

- Location, duration, temporal pattern, modifiers (better/worse)
- **Quality:**
 - **somatic:** dull/aching, well localized; fracture, bone metastases, muscle strain
 - **visceral:** dull/sharp/colicky; well localized or referred; gastritis, gallstones
 - **neuropathic:** burning, lancinating, itching; radicular or stocking-glove distribution, numb; Herpes zoster, spinal disk, diabetic neuropathy
- **Intensity:** 0–10 scale (0 = no pain; 10 = worst possible pain)
- **Treatments:** What the patient has used; drug and nondrug, response to treatments
- **Impact of pain on life:** activities of daily living, sleep, eating, movement, mood, work, hobbies
- Review patient understanding of pain causality
- Determine patient goals for pain relief (numeric 0–10, functional-sleep, moving)

Drug Therapy

Mild Pain

Over-the-counter drugs such as aspirin, acetaminophen, ibuprofen, naproxen; side effect profile and cost should determine choice of drug; no clear analgesic benefit of one drug compared with another

Moderate Pain

SINGLE AGENTS

- Codeine, 30 mg, 60 mg (tablet or liquid)
- Oxycodone, 5 mg (tablet or liquid)
- Tramadol, 50 mg, 100 mg,

COMBINATION PRODUCTS

- Acetaminophen with codeine, 30 mg, 60 mg
- Acetaminophen, 325–500 mg or aspirin, 325 mg, with oxycodone, 2.5–10 mg
- Acetaminophen, 325–750 mg or aspirin, 500 mg, with hydrocodone, 5–10 mg

Potency: oxycodone = hydrocodone > codeine = tramadol > propoxyphene

Duration: q 3–4 h for all products except tramadol (q 6 h)

Cost: generic codeine and oxycodone << hydrocodone products

NOTE: The acetaminophen or aspirin in combination products limits dose escalation; though the traditional maximum 24 hr dose of acetaminophen has been 4 grams, less than 3 grams/24 hours is recommended and considerably less should be used in the elderly and individuals with impaired hepatic function.

NOTES

Severe Pain

SHORT-ACTING DRUGS

Oral: onset, 15–30 minutes; peak effect, 60–90 minutes; duration, 2–4 hours

Parenteral: onset, 2–15 minutes; peak effect, 10–30 minutes; duration, 1–3 hours

- Morphine
- Hydromorphone
- Oxycodone
- Oxymorphone (duration 4–6 hours)
- **Meperidine:** shortest acting; use only for procedure-related pain; duration, less than 3 hours; use for 48 hours or less, no more than 600 mg/24 hours due to accumulation of toxic metabolite. *Best not to use meperidine at all.*

LONG-ACTING DRUGS

- Morphine sustained release: peak effect, about 2 hours; duration, 8–12 hours
- Oxycodone sustained release: peak effect, about 1–2 hours; duration, 8–12 hours
- Oxymorphone sustained release: peak effect, about 2–3 hours; duration, 12 hours
- Kadian (long-acting morphine preparation): peak effect, about 8 hours; duration, 12–24 hours
- Avinza (long-acting morphine preparation): peak effect, about 1 hour; duration, 12–24 hours
- Transdermal fentanyl: peak effect, 18–24 hours; duration, 48–72 hours (**Note:** 12–24 hours to wear off, once a patch is removed)

ULTRA-SHORT-ACTING DRUGS

- Transmucosal fentanyl (Actiq): for breakthrough pain; onset, 5–15 minutes; duration, 1–2 hours
- Fentanyl buccal (Fentora): for breakthrough pain; onset, 15 minutes; duration, 1–2 hours

Variable-duration drugs: continued use leads to longer duration of action (see Potency Ratio section)

Methadone, 6–12 hours; levorphanol, 4–8 hours

NOTES

POTENCY RATIOS (ESTIMATES)

30 mg oral morphine = 20–30 mg oral oxycodone
= 7.5 mg oral hydromorphone = 10 mg IV/SQ
morphine = 2 mg IV/SQ hydromorphone

**Fentanyl patch size (μg) = 24-hour oral
morphine dose divided by 2**

(Example: 30 mg q 12 h morphine sustained release = 60 mg PO morphine sulfate/24 h. Thus, approximate fentanyl patch strength equivalence = 60 divided by 2 = 30 μg . Round down to 25- μg patch q 72 h.)

NOTE: 2 oxycodone-acetaminophen (Percocet) q 4 h = 10 mg oral morphine q 4 h = 30 mg morphine sustained release q 12 h = 1 mg/h morphine sulfate continuous IV or SQ infusion = 25 μg fentanyl patch.

NOTE: Always calculate the equianalgesic value when changing from one opioid to another to avoid underdosing or overdosing. Consider dose reduction up to 50 percent when changing opioid owing to incomplete cross-tolerance.

Methadone: Methadone has an extended terminal half-life, up to 190 hours. This half-life does not match the observed duration of analgesia (6–12 hours) after steady state is reached. *This long half-life can lead to increased risk for sedation and respiratory depression, especially in elderly people or with rapid dose adjustments.* Methadone's apparent potency, compared with other opioids, varies with the patient's current exposure to other opioids.

Suggested Dosing Guide for Opioid Tolerant Patients*

Daily oral morphine dose equivalents (mg)	Conversion ratio of oral morphine to oral methadone
<100	3:1 (ie, 3 mg morphine:1 mg methadone)
101–300	5:1
301–600	10:1
601–800	12:1
801–1,000	15:1
>1,001	20:1

*Adapted from Ayonrinde OT, Bridge DT. The rediscovery of methadone for cancer pain management. *Med J Austral.* 2000;173:536–540; and Gazelle G, Fine PG. Fast Fact

and Concept #75: Methadone for the treatment of pain. 2nd ed. September 2002. Available at: http://www.eperc.mcw.edu/fastFact/ff_75.htm. Accessed July 28, 2009.

ROUTE

Oral is the preferred route; IV and SQ will produce equianalgesic effects, although IV will have the fastest onset of action. There is little, if any, indication for the IM route. Rectal is equianalgesic to oral. (Approved rectal preparations include morphine and hydromorphone. Sustained release morphine can be used rectally but is not approved for such use in the United States.)

DOSE ESCALATION AND FREQUENCY OF ADJUSTMENT

Escalate dose by 50 percent to 100 percent for severe or uncontrolled pain and 25 percent to 50 percent for mild to moderate pain, *irrespective of starting dose*. The doses of short-acting drugs can be escalated as often as every 1 or 2 hours, long-acting morphine/oxycodone every 24 hours, and a fentanyl patch or methadone no more frequently than every 48 to 72 hours.

PRESCRIBING RECOMMENDATIONS

- Use PRN orders only for truly episodic pain and when any patient receiving a long-acting opioid needs a short-acting opioid PRN for breakthrough pain.
- Never order more than one PRN opioid-nonopioid combination product at one time.
- Use a continuously administered opioid for continuous pain (for example, long-acting morphine or fentanyl patch); never order more than one long-acting product at a time.
- Do not use dosing modifiers (for example, oxycodone-acetaminophen [Percocet] PRN for *moderate* pain).
- Use equianalgesic tables to calculate doses when changing drug or route.
- Prescribing less than usual long-term pain medication postoperatively may result in physical withdrawal symptoms, needless pain, and likely noncompliance with the recommended treatment regimen.

NOTE: Consider 50 percent dose reduction when changing drug owing to incomplete cross-tolerance.

TOXIC EFFECTS

- Constipation: prophylaxis with bowel stimulant (senna or milk of magnesia)
- Nausea: **is not an allergy**; will resolve after a few doses for most patients; use an antiemetic PRN (such as prochlorperazine)
- Sedation and confusion: will resolve after a few doses or days for most patients
- Respiratory depression: *very rare with short-acting oral opioids. . .when using recommended starting doses*; tolerance develops rapidly; risk factors include rapid IV push administration, new hepatic or renal dysfunction, severe lung disease, rapid dose escalation of fentanyl patch or methadone
- Pruritus: common, especially with morphine, least reported with fentanyl; not a true allergy; not a contraindication to opioid use; H₁/H₂ blockers usually not helpful; switch to opioid of a different pharmacologic class
- Neurotoxicity: multifocal myoclonus, delirium, and seizures with morphine and hydromorphone, especially at high doses or in renal failure
- Prolonged QT interval: risk of torsades de pointes with methadone

TOLERANCE AND ADDICTION

- Tolerance: need to increase dose to get same effect; tolerance *not* the same as addiction
- Physical dependence: withdrawal reaction if drug discontinued or antagonist given; physical dependence *not* the same as addiction; all patients taking long-term opioids develop physical dependence
- Psychological dependence (addiction): overwhelming involvement with acquisition and use of drug for nonmedical purposes; no improvement in quality of life; best defined as “loss of control” or “use despite harm”
- Pseudoaddiction: behaviors suggesting addiction that are due to inadequately treated pain

NOTES

Adjuvant Analgesics

Antidepressants: All tricyclic antidepressants have analgesic effects. Start at a low dose, and escalate the dose slowly (every 2–3 days) to maximally tolerated dose; discontinue if no response within 1 week at maximal dose. (Note: There is no evidence for superior analgesia with amitriptyline, which is maximally anticholinergic, especially problematic in elderly people.) Among the selective serotonin reuptake inhibitor–serotonin-norepinephrine reuptake inhibitor class, only serotonin-norepinephrine reuptake inhibitors appear to have analgesic effects (venlafaxine, duloxetine).

Anticonvulsants: Gabapentin and pregabalin have become quite popular owing to their ease of use—no blood levels to monitor, few side effects—but these products are costly. Older drugs such as phenytoin, carbamazepine, and valproic acid all have demonstrated analgesic effects but need to be monitored carefully by blood levels. Discontinue an anticonvulsant if there is no effect at maximally tolerated doses or optimal blood levels.

Corticosteroids: These drugs are of limited long-term use owing to side effects. Dosing is empiric: dexamethasone, 2 to 8 mg/d; prednisone, 20 to 80 mg/d.

Systemic local anesthetics: IV lidocaine may offer relief for refractory neuropathic pain.

Local anesthetics: Topical lidocaine as a cream (EMLA) or patch (Lidoderm) can provide local anesthesia. The patch is approved for use in postherpetic neuralgia and used anecdotally for many other neuropathic pain conditions.

Ketamine: Anecdotal experience suggests there is efficacy when used orally or IV for neuropathic pain.

Nondrug Therapy

- Physical modalities: heat, cold, massage, physical therapy, stretching, therapeutic touch, transcutaneous electrical nerve stimulation (or TENS), acupuncture
- Behavioral treatments: relaxation, music therapy, imagery, education, reframing, biofeedback, psychotherapy
- Antineoplastic therapies for cancer pain: external beam radiation, radiopharmaceuticals, chemotherapy, hormonal therapy
- **Other:** discussion of anesthetic and neurosurgical treatments beyond the scope of this book

NOTES

Bibliography

- Acute Pain Management Guideline Panel. *Acute Pain Management: Operative or Medical Procedures and Trauma Clinical Practice Guideline*. Rockville, MD: Agency for Health Care Policy and Research, US Department of Health and Human Services, Public Health Service; 1992. AHCPR publication 92-0032.
- American Pain Society Quality of Care Committee. Quality improvement guidelines for the treatment of acute pain and cancer pain. *JAMA*. 1995;273:1874–1880.
- Arnold R, Verrico P, Davison SN. Fast Fact and Concept #161: Opioid use in renal failure. August 2006. Available at: http://www.eperc.mcw.edu/fastFact/ff_161.htm. Accessed July 28, 2009.
- Arnold R, Weissman DE. Fast Fact and Concept #036: Calculating opioid dose conversions. 2nd ed. July 2005. Available at: http://www.eperc.mcw.edu/fastFact/ff_036.htm. Accessed July 28, 2009.
- Ayonrinde OT, Bridge DT. The rediscovery of methadone for cancer pain management. *Med J Austral*. 2000;173:536–540.
- Backonja M, Beydoun A, Edwards KR, et al. Gabapentin for symptomatic treatment of painful neuropathy in patients with diabetes mellitus. *JAMA*. 1998;280:1831–1836.
- Bell RF, Eccleston C, Kalso E. Ketamine as adjuvant to opioids for cancer pain: a qualitative systematic review. *J Pain Symptom Manage*. 2003;26(3):867–875.
- Breitbart W, Chandler S, Eagle B, et al. An alternative algorithm for dosing transdermal fentanyl for cancer pain. *Oncology*. 2000;14:695–702.
- Challapalli V, Tremont-Lukats IW, McNicol ED, et al. Systemic administration of local anesthetic agents to relieve neuropathic pain. *Cochrane Database Syst Rev*. 2005(4):CD003345.
- Dunwoody CJ, Arnold R. Fast Fact and Concept #039: Using naloxone. 2nd ed. July 2005. Available at: http://www.eperc.mcw.edu/fastFact/ff_39.htm. Accessed July 28, 2009.
- Galer BS, Jensen MP, Ma T, et al. The lidocaine patch 5% effectively treats all neuropathic pain qualities: results of a randomized, double-blind, vehicle-controlled, 3-week efficacy study with use of the neuropathic pain scale. *Clin J Pain*. 2002;18:297–301.
- Gazelle G, Fine PG. Fast Fact and Concept #75: Methadone for the treatment of pain. 2nd ed. September 2002. Available at: http://www.eperc.mcw.edu/fastFact/ff_75.htm. Accessed July 28, 2009.
- Gordon D. Fast Fact and Concept #53: Sublingual morphine. 2nd ed. July 2006. Available at: http://www.eperc.mcw.edu/fastFact/ff_53.htm. Accessed July 28, 2009.
- Gordon D, Schroeder M. Fast Fact and Concept #103: Oral transmucosal fentanyl citrate-OTFC (Actiq). December 2003. Available at: http://www.eperc.mcw.edu/fastFact/ff_103.htm. Accessed July 28, 2009.
- Gordon DB. Fast Fact and Concept #70: PRN range analgesic orders. 2nd ed. July 2006. Available at: http://www.eperc.mcw.edu/fastFact/ff_70.htm. Accessed July 28, 2009.
- Jacox A, Carr DB, Payne R, et al. *Clinical Practice Guideline No. 9: Management of Cancer Pain*. Rockville, MD: Agency for Health Care Policy and Research, US Department of Health and Human Services, Public Health Service; 1994. AHCPR publication 94-0592.
- Kishore A, King L, Weissman DE. Fast Fact and Concept #049: Gabapentin for neuropathic pain. 2nd ed. August 2005. Available at: http://www.eperc.mcw.edu/fastFact/ff_49.htm. Accessed July 28, 2009.
- Prommer E. Fast Fact and Concept #92: Patient controlled analgesia in palliative care. 2nd ed. November 2007. Available at: http://www.eperc.mcw.edu/fastFact/ff_92.htm. Accessed July 28, 2009.
- Prommer E. Fast Fact and Concept #132: Ketamine use in palliative care. March 2005. Available at: http://www.eperc.mcw.edu/fastFact/ff_132.htm. Accessed July 28, 2009.
- Portenoy RK. Continuous infusion of opioid drugs in the treatment of cancer: guidelines for use. *J Pain Symptom Manage*. 1986;1:223–228.
- Rosielle DA. Fast Fact and Concept #166: Once-daily oral morphine formulations. October 2006. Available at: http://www.eperc.mcw.edu/fastFact/ff_166.htm. Accessed July 28, 2009.
- Storey P, Hill HH Jr, St Louis RH, et al. Subcutaneous infusions for control of cancer symptoms. *J Pain Symptom Manage*. 1990;5:33–41.
- Teuteberg WG. Fast Fact and Concept #142: Opioid-induced hyperalgesia. September 2005. Available at: http://www.eperc.mcw.edu/fastFact/ff_142.htm. Accessed July 28, 2009.
- von Gunten CF. Fast Fact and Concept #86: Methadone: starting dose information. 2nd ed. January 2008. Available at: http://www.eperc.mcw.edu/fastFact/ff_86.htm. Accessed July 28, 2009.
- Weinstein E, Arnold B. Fast Fact and Concept #129: Steroids in the treatment of bone pain. January 2005. Available at: http://www.eperc.mcw.edu/fastFact/ff_129.htm. Accessed July 28, 2009.
- Weinstein E, Arnold R, Weissman DE. Fast Fact and Concept #54: Opioid infusions in the imminently dying patient. 2nd ed. September 2006. <http://www.eperc.mcw.edu>. Accessed July 28, 2009.

- Weissman DE. Fast Facts and Concepts #2: Converting to/from transdermal fentanyl. 2nd ed. July 2005; updated September 2008. Available at: http://www.eperc.mcw.edu/fastFact/ff_002.htm. Accessed July 28, 2009.
- Weissman DE. Fast Fact and Concept #020: Opioid dose escalation. 2nd ed. July 2005. Available at: http://www.eperc.mcw.edu/fastFact/ff_020.htm. Accessed July 28, 2009.
- Weissman DE. Fast Fact and Concept #025: Opioids and nausea. 2nd ed. August 2005. Available at: http://www.eperc.mcw.edu/fastFact/ff_025.htm. Accessed July 28, 2009.
- Weissman DE. Fast Fact and Concept #28: Subcutaneous infusions. 2nd ed. July 2005. Available at: http://www.eperc.mcw.edu/fastFact/ff_028.htm. Accessed July 28, 2009.
- Weissman DE. Fast Fact and Concept #51: Choosing an opioid combination product. 2nd ed. July 2006. Available at: http://www.eperc.mcw.edu/fastFact/ff_51.htm. Accessed July 28, 2009.
- Weissman DE. Fast Fact and Concept #68: Is it pain or addiction? 2nd ed. July 2006. Available at: http://www.eperc.mcw.edu/fastFact/ff_68.htm. Accessed July 28, 2009.
- Weissman DE. Fast Fact and Concept #69: Pseudoaddiction. 2nd ed. July 2006. Available at: http://www.eperc.mcw.edu/fastFact/ff_69.htm. Accessed July 28, 2009.
- Weissman DE. Fast Fact and Concept #71: Meperidine for pain: what's all the fuss? 2nd ed. July 2006. Available at: http://www.eperc.mcw.edu/fastFact/ff_71.htm. Accessed July 28, 2009.
- Weissman DE. Fast Fact and Concept #72: Opioid infusion titration orders. 2nd ed. July 2006. Available at: http://www.eperc.mcw.edu/fastFact/ff_72.htm. Accessed July 28, 2009.
- Weissman DE. Fast Fact and Concept #74: Oral opioid orders: good and bad examples. 2nd ed. July 2006. Available at: http://www.eperc.mcw.edu/fastFact/ff_74.htm. Accessed July 28, 2009.
- Weissman DE. Fast Fact and Concept #80: Oxycontin. 2nd ed. October 2007. Available at: http://www.eperc.mcw.edu/fastFact/ff_80.htm. Accessed July 28, 2009.
- Wilner LS, Arnold R. Fast Fact and Concept #126: Pain assessment in the cognitively impaired. November 2004. Available at: http://www.eperc.mcw.edu/fastFact/ff_126.htm. Accessed July 28, 2009.
- Woodall HE, Chiu A, Weissman DE. Fast Fact and Concept #175: Opioid allergic reactions. February 2007. Available at: http://www.eperc.mcw.edu/fastFact/ff_175.htm. Accessed July 28, 2009.

Diagnosis and Management of Psychiatric Disorders in Patients with Pain

Substance Use and Abuse Definitions

Tolerance: The need to increase the amount of drug to obtain the same effect

Physical dependence: Development of withdrawal reaction on discontinuation or antagonism of drug

Pseudoaddiction: Behavioral manifestations of addiction occurring as a result of undertreated pain; typically in the setting of severe continuous pain when drugs are administered at inadequate doses at excessive dosing intervals

Addiction; also called psychological dependence: Overwhelming involvement in the acquisition and use of drugs for nonmedical purposes characterized by one or more of the following behaviors: impaired control over drug use, compulsive use, continued use despite harm, and craving; tolerance and physical dependence may or may not be present; presence of tolerance or physical dependence does not prove psychological dependence

CRITERIA SUGGESTING A SUBSTANCE USE DISORDER INCLUDE THE FOLLOWING:

- Continued use despite negative personal, medical, and legal problems
- Frequent intoxication at times when one is expected to fulfill major life roles or when substance abuse is dangerous
- Much time spent in obtaining, using, and thinking about drugs
- Reduction in important social, occupational, or recreational activities owing to substance abuse

Substance Abuse Assessment

Obtain a thorough pain assessment, including quantitation, quality, descriptors, and impact on activities of daily living. Obtain a complete database of information relative to concerns you may have regarding addiction. Important questions related to addiction assessment include the following: (Note: Multiple clues from the following list are typically present to establish a diagnosis of substance abuse.)

1. Treatment plan reliability
 - Compliance with prescribed drugs
 - Follow-up with clinic visits and recommended consultations
2. Loss of control of drug use
 - Partially used bottles of medications at home argues against addiction
3. Adverse life consequences
 - Loss of job, marriage, children owing to drugs
 - Legal and medical problems owing to drugs
4. Drug-seeking behaviors
 - “Lost medications”
 - Demands for drugs of high street value
 - “Allergies” to many opioids
 - Prescriptions from many physicians filled at many pharmacies; emergency department visits for refills
5. Abuse of other drugs
 - Alcohol, benzodiazepines, cocaine, heroin, amphetamines
6. Contact with street culture
 - Friends/family who are users

NOTES

Other Psychiatric Disorders that Often Manifest as Pain

1. **Psychiatric comorbidity**—primary psychiatric diagnoses in which pain is commonly the presenting complaint
 - Depression; panic or anxiety attacks
 - Physical or sexual abuse; posttraumatic stress disorder
2. **Somatization disorder**

In women much more often than in men; begins before age 30 years

 - *DSM-IV* diagnostic criteria:

History of somatic symptoms prior to age 30

History of pain affecting at least four different parts or functions of the body.

History of at least two gastrointestinal symptoms

History of at least one sexual or reproductive symptom

One symptom mimicking a neurological condition such as fainting or blindness

 - Complaints cannot be explained or seem excessive
 - Symptoms are not intentional
 - Patients feel pain.
3. **Pain associated with psychological factors** (old terms were psychogenic pain, and somatoform disorder)
 - Pain in one or more anatomic areas is sufficient to seek medical attention.
 - Pain causes significant distress or impairment with social or occupational function.
 - Psychological factors have an important role in pain onset, severity, and maintenance of the pain.
 - Symptoms are not intentional.
 - Patients feel pain.
4. **Hypochondriasis**
 - Preoccupation with the belief or fear of a serious disease
 - In men and women equally; can occur in later life
 - Exaggerated sense of bodily symptoms
 - Patients feel pain.
5. **Factitious disorder**
 - Primary gain is fulfillment of a psychological need
 - Symptoms are produced consciously, although motivation may be unconscious
 - Purely fictitious problem or a self-created problem (for example, by an insulin injection)
 - Very willing to undergo invasive procedures
 - Improvements followed by relapse
 - Patient can forecast exacerbation
 - Patient resists psychiatric consult
 - There is poor continuity of care, and multiple physicians are seen.
6. **Malingering (consciously motivated)**
 - Primary need is a secondary gain:
 - Relief from noxious events: work, jail
 - Narcotics to abuse or sell (income source)
 - Monetary award from litigation or disability
 - Patients are less willing to undergo invasive procedures.

NOTES

Management

1. **Establish a diagnosis.** Do you believe the patient has pain due to a physical malady (such as bone metastases, nerve root damage, bowel obstruction); a psychological or psychiatric disorder; or spiritual (existential pain)? If you are not sure following completion of a routine pain assessment, complete a thorough psychiatric examination, including a substance abuse assessment.
2. **Anticipatory management.** For elective procedures, establish the expected postoperative pain and the patient's expected level of pain. Use of standard pain scales to determine the level of pain the patient expects is useful postoperatively to patients, nurses, and physicians.
3. **Pain assessment pearls.** There is no reliable indicator of pain; therefore, autonomic signs or physical behaviors (such as crying and grimacing) are not useful for deciding when a patient is in pain. Similarly, complaints of pain that appear exaggerated to what we expect is "normal" for a particular condition are likely to reflect cultural differences in pain expression, pseudoaddiction, or worsening tissue damage and, thus, are not reliable indicators of a substance abuse disorder. Placebos should be avoided because they instill mistrust and are unreliable in establishing a diagnosis of addiction or "true" pain.
4. **Seek consultation.** Ask for assistance from a substance abuse/mental health professional if you are not sure of the diagnosis. Remember, a substance use disorder is a treatable condition.
5. **Patient involvement.** Involve the patient in the pain treatment plan; discuss with the patient what will be available and how you will respond if the pain is not adequately treated.

6. Pharmacological options

Opioids: Medications to treat pain should be prescribed in appropriate doses and intervals whether or not the patient has a substance use disorder. Restricting doses and prescribing at excessive intervals will encourage behaviors that may suggest pseudoaddiction in a patient with pain.

- a. **Choice of drug:** For mild to moderate pain, NSAIDs, acetaminophen, or weak opioid-nonopioid combinations should be used. Note that the combination products (such as acetaminophen with codeine [Tylenol #3] and oxycodone-acetaminophen [Percocet]) should be prescribed q 4 h, not q 6 h. For moderate to severe pain, there is no "best" opioid. However, the drug of choice for moderate to severe pain is morphine. Meperidine use should be discouraged due to its toxic metabolite and short duration of action. Prescribe opioids with a fixed dose and interval that make pharmacologic sense (such as morphine sulfate, 10 mg PO q 4 h), using PRN dosing only if pain is truly episodic. Do not specify a wide range of doses or dosing intervals or use pain descriptors (for example, meperidine 50–75 mg q 4–6 h prn for severe pain). If the patient has known addiction and also has pain, it is best to avoid parenteral dosing and short-acting drugs; use long-acting oral agents when possible.
- b. **Choice of route:** Oral drugs are preferred; the IM route should be discouraged because there is no indication for this unnecessarily painful method of drug delivery.

Nonopioids: Many alternative drugs can be useful, including NSAIDs, anticonvulsants, antidepressants, and others. **Note:** The benzodiazepines (such as lorazepam [Ativan]) and antihistamines (such as hydroxyzine [Atarax, Vistaril]) are frequently given to patients with pain; these agents are not analgesics, they typically cause sedation but by themselves result in no significant pain relief.

7. **Nonpharmacologic treatments.** Heat and cold application, TENS, massage, behavioral treatments, and more invasive procedures such as nerve blocks or spinal opioids can be helpful.

NOTES

8. **Discharge planning.** The transition to the outpatient setting is typically the weakest link in patient management. All patients with frequent episodes of severe acute pain or chronic nonmalignant pain, for which a decision has been made to prescribe long-term opioids, need careful and consistent follow-up. For patients with a known substance abuse problem or patients in recovery, effective follow-up is especially necessary. General principles of management, which should be established before discharge, include the following:
- Consider using a written treatment plan (opioid contract) that specifies the physician and patient responsibilities and consequences for the patient of noncompliance.
 - Only one designated physician should prescribe medications, using only one dispensing pharmacy.
 - Seek consultation with an addiction specialist and/or pain management specialist when appropriate.
 - Patients in recovery should be urged to restart or increase involvement in drug-abstinence programs.

Bibliography

- American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*. Arlington, VA: American Psychiatric Association; 1994.
- Eisendrath SJ. Psychiatric aspects of chronic pain. *Neurology*. 1995;45(12 suppl 9):S26–S34.
- Fishman SM, Bandman TB, Edwards A, et al. The opioid contract in the management of chronic pain. *J Pain Symptom Manage*. 1999;18:27–37.
- Passik SD, Kirsh KL, Donaghy KB et al. Pain and aberrant drug-related behaviors in medically ill patients with and without histories of substance abuse. *Clin J Pain*. 2006;22(2):173–181.
- Passik SD, Kirsh KL. Managing pain in patients with aberrant drug-taking behaviors. *J Support Oncol*. 2005;3(1):83–86.
- Passik SD, Kirsh KL. Assessing aberrant drug-taking behaviors in the patient with chronic pain. *Curr Pain Headache Rep*. 2004;8(4):289–294.
- Portenoy RK. Chronic opioid therapy in non-malignant pain. *J Pain Symptom Manage*. 1990;5(suppl):S49–S62.
- Sees KL, Clark HW. Opioid use in the treatment of chronic pain: assessment of addiction. *J Pain Symptom Manage*. 1993;8:257–264.
- Wesson DR, Ling W, Smith DE. Prescription of opioids for treatment of pain in patients with addictive disease. *J Pain Symptom Manage*. 1993;8:289–296.

NOTES

Pain Assessment and Management Case Studies | Faculty Guide

CASE 1. Selection and Titration of Opioids for Severe Pain

Objectives

1. List barriers to analgesic management.
2. Practice writing analgesic orders for severe pain.
3. Practice equianalgesic conversion calculations.

CASE 2. Differentiating “Real” Pain From Addiction

Objectives

1. Examine personal attitudes toward drug addiction and pain management.
2. Define tolerance and physical and psychological dependence (addiction).
3. Plan a pain management strategy for a patient with a history of substance abuse.

CASE 3. Respiratory Depression

Objectives

1. Describe patient and drug risk factors for opioid-induced respiratory depression.
2. Plan a management strategy for avoiding respiratory depression.
3. Plan a management strategy for suspected opioid-induced respiratory depression in a dying patient.
4. Explain the difference between euthanasia, physician-assisted suicide, and good pain management.

CASE 4. Management of Severe Mixed Somatic and Neuropathic Pain

Objectives

1. Differentiate between somatic and neuropathic pain.
2. Describe drug and nondrug treatment strategies for somatic and neuropathic pain.
3. Develop a management plan for a common cancer-related pain syndrome.

CASE 1. Selection and Titration of Opioids for Severe Pain

Objectives

List barriers to analgesic management.

1. Practice writing analgesic orders for severe pain.
2. Practice equianalgesic conversion calculations.

A 50-year-old patient with metastatic breast cancer is admitted to the hospital at 1:00 am because of severe neck pain. She is unable to move her head because of the pain, which has gradually worsened during the last 2 weeks. She has been taking an increasing amount of Percocet with little effect, most recently 2 Percocet tablets q 4 h. She is seen by the on-call physician and the following orders are written: morphine, 10–15 mg PO q 4–6 h PRN for severe pain; Tylenol #3, 1–2 tablets PO q 6 h PRN for mild to moderate pain. Diagnostic radiographs have been ordered to evaluate for possible spinal cord compression. The next morning (8 hours after admission), she is still in severe pain, no better than she was before admission; none of the diagnostics have been done because the patient was in too much pain. You check the chart and find there have been several one-time verbal orders for IV morphine, 2 mg. You discuss the situation with the current nurse who relates that during the night, the physician on call was reluctant to increase the medicine dose out of fear of respiratory depression.

Questions

1. List at least four problems with the analgesic orders as written.
2. For the drugs listed below, calculate the 24-hour dose that would be equianalgesic with 2 Percocet tablets q 4 h. (Each Percocet tablet contains 5 mg of oxycodone and 325 mg of acetaminophen.)
 - Oral morphine, immediate release (MSIR)
 - Oral morphine, extended release (MSER)
 - IV morphine infusion
 - Subcutaneous morphine infusion
 - Oral hydromorphone
 - Transdermal fentanyl
3. What is a reasonable time frame in which to expect improved analgesia for this patient?
4. What principles would you use to decide how fast and by how much you would escalate the opioid dose?
5. What would have been a better way to write the admission analgesic orders? List two sets of admitting orders, one using oral opioids, the other using parenteral opioids.

CASE 1. Faculty Guide—Inadequately Prescribed Opioids

1. Allow the participants to express their ideas about better admitting orders and when to use PRN versus around-the-clock dosing. Discuss the problems associated with the use of dosing ranges. The problems with the orders as written include the following (1) range of doses, (2) range of dosing intervals, (3) PRN dosing for continuous pain, and (4) use of descriptors—mild, moderate, and severe.

NOTES

2. Equianalgesic calculations are as follows:

- a. 2 Percocet q 4 h = 10 mg oxycodone
q 4 h = 60 mg oxycodone/24 h

Look up the equivalent analgesic doses of oral oxycodone and oral morphine in any current equianalgesic table: 30 mg of oral oxycodone is equivalent to 20 to 30 mg of oral morphine.

Therefore, 60 mg oral oxycodone/24 h ≈ 60 mg of oral morphine/24 h

$$= 10 \text{ mg MSIR q 4 h} = 30 \text{ mg MSER q 12 h}$$

- b. Look up the equivalent analgesic doses of oral oxycodone and parenteral morphine in an equianalgesic table: 30 mg of PO oxycodone is equivalent to 10 mg of parenteral morphine

$$\frac{30 \text{ mg PO oxycodone}}{60 \text{ mg PO oxycodone}} = \frac{10 \text{ mg IV morphine}}{X \text{ mg IV morphine}}$$

$$X = 20 \text{ mg IV morphine/24 h or } \sim 1 \text{ mg IV morphine/h}$$

- c. Doses of SQ and IV morphine are the same.
d. Doses of SQ and IV morphine are the same.
e. Look up the equivalent analgesic doses of oral oxycodone and oral hydromorphone in an equianalgesic table: 30 mg of oral oxycodone is equivalent to 7.5 mg of oral hydromorphone.

$$\frac{30 \text{ mg PO oxycodone}}{60 \text{ mg PO oxycodone}} = \frac{7.5 \text{ mg PO hydromorphone}}{X \text{ mg IV morphine}}$$

$$X = 15 \text{ mg PO hydromorphone/24 h} = \text{hydromorphone } 2.5 \text{ mg q 4 h}$$

- f. The manufacturer suggests that a 25- μ g fentanyl patch is equivalent to 45 to 134 mg of oral morphine/24 h; therefore, the calculated oral morphine dose of 60 mg/24 h would suggest that an equianalgesic dose of fentanyl would be 25 μ g q 72 h. A more user-friendly way to convert dosing from morphine to fentanyl is as follows:
24-h oral morphine dose in mg/2 = fentanyl patch size

1. Discuss a reasonable time frame in which to expect better analgesia. Certainly within the first 1 or 2 hours, a patient in severe pain should be at least 50 percent improved and have improvement in activities of daily living. The important point is that the dose of opioid can and should be adjusted frequently within the first few hours if pain is not quickly relieved. If rapid dose adjustments fail to make any impact, then other measures will be needed.
2. As a general rule, for moderate to severe pain, escalate the dose by 50 to 100 percent mild pain, increase by 25%. Always escalate the dose by a **percentage** of the prior dose (no matter what the current basal dose is). Doses of short-acting opioids (MSIR, oxycodone, hydromorphone) can be escalated every hour, whereas doses of MSER and oxycodone can be escalated every 24 hours; doses of the fentanyl patch and methadone can be escalated no more frequently than every 72 hours. When IV infusions are increased, a bolus dose should be given to rapidly increase the blood level.
3. Discuss a reasonable set of admitting orders (there is no "right" answer), for example, calculate the appropriate starting doses for oral and parenteral morphine.

- **Oral dosing**

- i. Morphine 20 mg PO q 4 h with morphine 10 mg q 1 h PRN pain *or*
- ii. MSER 60 mg q 12 h with morphine 10 mg q 1 h PRN
- iii. Call the physician within 1 hour to report on patient's condition.

- **IV dosing**

- i. Morphine drip at 2 mg/h after a bolus dose of 5 to 10 mg IV with 5 mg q 15 min PRN
- ii. Call the physician with 1 hour to report on patient's condition.

NOTES

CASE 2. Differentiating “Real” Pain from Addiction

Objectives

1. Examine personal attitudes toward drug addiction and pain management.
2. Review definitions of tolerance and physical and psychological dependence (addiction).
3. Plan a pain management strategy for a patient with a history of substance abuse.

A 25-year-old man has been hospitalized for 2 weeks after a motor vehicle collision in which he sustained multiple facial fractures, rib fractures, a mild traumatic brain injury, and a femur fracture. His femur and face have been operatively fixed, and he is receiving a fractured jaw diet. He describes his pain as “really bad,” and it is not relieved by acetaminophen with codeine elixir ordered q 4 h PRN.

The patient repeatedly asks for something before the 4-hour dosing interval and is often seen moaning. The physician is concerned about using an opioid of greater potency or administering opioids more frequently because the patient admitted to a history of polydrug abuse, although none in the last 2 years. The nurses are angry with the patient because of his repeated requests for medication and have written in the chart that the patient is drug seeking, possibly an addict.

You are asked to see the patient as a “pain consultant.” After your assessment, you recommend a change to morphine elixir, 15 mg q 4 h around-the-clock. The resident calls you after reading your consult note and says: “I appreciate your consult, but I really think this patient is drug seeking and I don’t feel comfortable with your recommendations. Let me think it over; I was thinking of asking a psychiatrist to see him to help with addiction management.” The next day you check the chart and find that your suggestion has not been taken but the acetaminophen with codeine was discontinued in place of oxycodone-acetaminophen elixir q 4 h PRN. During the next several days, the patient is still complaining of pain, but no new analgesic orders have been written.

Questions

1. Put yourself in the position of the resident physician or staff nurse. What are their major concerns about providing stronger analgesics for this patient? List at least four fears or concerns.
2. Is this patient a drug addict? List criteria you would use to decide that the patient was drug seeking for illicit or euphoric purposes rather than for relief of pain.
3. As the pain consultant, what would you do? What arguments or educational techniques could you use to help convince the resident to follow your recommendations?

CASE 2. Faculty Guide—Pain vs Addiction

The primary goals of this case are to have participants discuss their own feelings about psychological dependence as a barrier to the prescribing of opioids and to better understand the fears and concerns of their colleagues.

First, it will be important to determine that the participants know the meaning of the terms tolerance and physical and psychological dependence (addiction) and then to determine how their concerns about these phenomena affect prescribing, dispensing, or administering.

Discussion points

1. Common fears that will likely be discussed (if not you should discuss them):
 - Fear of making the patient an addict
 - Fear of loss of control as the health care provider; fear of being duped
 - Fear of malpractice, if the patient sues you for making him an addict
 - Fear of regulatory review by the Drug Enforcement Agency
 - Fear of respiratory depression in the patient
 - Fear of negative sanctions by colleagues or hospital

NOTES

2. Make a list on the flip-chart that participants come up with as possible criteria for drug addiction--it will likely look something like this:
 - a. Body language
 - b. Facial grimacing
 - c. Clock watching
 - d. Demanding behavior
 - e. Finding used syringes or needles in the room
 - f. Being overly sedated after “friends” visit
 - g. Any history of drug abuse
 - h. Asking for or demanding specific drugs
 - i. Having drug allergies to many opioids (typically to morphine but not to hydromorphone or meperidine)
 - j. Admitting to living in an environment where family/friends are actively using drugs

Discuss that items a through d are consistent with true addiction or pseudoaddiction; there is no way to differentiate without further information or a trial of better pain relief. Items e through f are pretty good indicators of true addiction, especially e. Items h through j are suggestive but not diagnostic; item g indicates a history but says nothing about the present.

The total pattern of behavior and recent and remote history are necessary to make the diagnosis of substance abuse. Ensure that everyone understands the definitions and differences in tolerance and physical and psychological dependence (addiction); if needed, review the criteria in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* for substance abuse/substance dependence and pain disorders.

3. Discuss techniques for dealing with reluctant clinicians, such as the following:

Assessment: Improve the assessment process so that patients are participating more in their care; review in greater depth the history of drug abuse, any history of drug abuse treatment; and explore patient concerns about drug use.

Reverse role-playing: Have one team member play the patient and ask for his or her response (What would you do?) to inadequate treatment of severe pain.

Provide positive information to clinicians: Make sure they understand what addiction is and is not; make sure they understand the consequences of untreated pain; provide resource material.

Cognitive therapy: Have clinicians discuss the worst possible consequences to providing more analgesics, including malpractice litigation, respiratory depression, and negative sanctions by colleagues or state regulatory authorities, and allow them to understand that their fears are generally not based in reality. (However, in some states, the threat of regulatory scrutiny is real. This issue should not be dismissed lightly).

Patient involvement: Make sure everyone understands that the patient should be included when establishing a care plan.

NOTES

CASE 3. Respiratory Depression

Objectives

1. Describe patient and drug risk factors for opioid-induced respiratory depression.
2. Plan a management strategy for avoiding respiratory depression.
3. Plan a management strategy for suspected opioid-induced respiratory depression in a dying patient.
4. Explain the difference between euthanasia, physician-assisted suicide, and good pain management.

A 76-year-old woman with end-stage metastatic breast cancer and severe chronic obstructive pulmonary disease undergoes laparotomy to relieve an adhesive bowel obstruction. She recovers relatively well but complains of severe back pain, likely due to bony metastases seen on her last bone scan, exacerbated by postoperative immobility. She rates the pain at 9/10, severely limiting movement. The pain is poorly relieved by 120 mg q 8 h of MSER and ibuprofen, 600 mg q 6 h. The patient understands her condition is “terminal” and wants maximal pain relief.

The nurse contacts you and asks to have the dose of opioid increased. The new order is for MSER 150 mg q 8 h with MSIR 15 mg q 4 h for breakthrough pain. This does not reduce the severity of pain, and the dose of breakthrough MSIR is not effective either. The nurse suggests increasing the MSER to 300 mg q 8 h. You are concerned that owing to the patient’s chronic obstructive pulmonary disease, she is at increased risk for opioid-induced respiratory depression.

QUESTIONS

1. What are the patient and drug risk factors for respiratory depression?
2. If the patient’s respiratory rate dropped to 6 to 8 breaths per minute while she was asleep, what would you do?
3. What would be your legal liability if this patient died soon after a dose of morphine? Would this be euthanasia?

NOTES

CASE 3. Faculty Guide—Respiratory Depression

1. Tolerance develops rapidly to the central nervous system depressant effects of opioids. Risk factors for respiratory depression include rapid dose escalation, particularly of methadone, fentanyl patch, or levorphanol; rapid bolus IV dosing; severe lung disease; and new hepatic or renal dysfunction.

A falling respiratory rate is normal when patients receive opioids, especially while sleeping. The first step in management is to assess the level of consciousness. If the patient is not arousable, then astute clinical judgment must be exercised. Is the patient imminently or actively dying from his illness? If not, would the patient wish to be treated for over dosage, even if it was unintentional? If treated for over dosage, would the patient accept the risk of recurrent severe pain that can occur with rapid reversal of opioids? If opioid induced respiratory depression is to be treated, naloxone (Narcan) can be administered by IV bolus or by slow IV infusion (dilute 1 ampule in 10 mL of saline; give 1 mL every 60 seconds until the level of consciousness increases).

A slow infusion is generally preferred in nonemergency situations because a slow infusion can reverse opioid effects in a step-wise manner—from coma to sleep to awake with analgesia—without inducing opioid withdrawal and severe pain.

1. Discuss concerns about a patient dying while receiving morphine: there is nothing ethically or legally inappropriate about a patient dying during a morphine infusion or after a bolus dose as long as the *intent* was to relieve pain. However, death directly attributable to opioid-induced respiratory depression should occur very rarely. However, death directly attributable to opioid-induced respiratory depression should occur very rarely in properly supervised situations.

Definitions

Euthanasia—intentionally causing the death of a patient through the direct administration of a drug or device with the intention of causing death.

Physician-assisted suicide—providing the patient with a means to end his or her life (typically giving the patient a prescription for a lethal dose of a medication to take at the time and place of his or her choosing).

Good pain management—providing sufficient medication with the intent to relieve suffering; the risk of iatrogenic respiratory depression when managed carefully is extremely small, even shortly before death.

Bibliography

Fohr S. The double effect of pain medication: separating myth from reality. *J Palliat Med.* 1998;1:315–328.

CASE 4. Management of Severe Mixed Somatic and Neuropathic Pain

Objectives

1. Differentiate between somatic and neuropathic pain.
2. Describe drug and nondrug treatment strategies for somatic and neuropathic pain.
3. Develop a management plan for this persistent pain syndrome.

A 35-year-old man sustains a gunshot wound to the low back; a computed tomography scan confirms lack of intraabdominal injury, and he is discharged from the emergency department with oxycodone, 10 mg every 4 hours.

He is seen in the clinic 2 weeks later and is complaining of severe right lower extremity pain he describes as constant and burning. Review of the computed tomography scan shows the path of the bullet in proximity to the right L5 nerve root and the sciatic nerve.

QUESTIONS

1. Classify this patient's pain type.
2. How would you change his opioid prescription to provide better analgesia? List three alternative strategies: drug, dose, and dosing intervals.
3. If you decide to use an antidepressant as an adjuvant, what drug and dose would you start with? How fast would you escalate the dose, and what end point would you use to decide if the drug is not effective and should be stopped?
4. What alternative agent would you consider for management of neuropathic pain if an antidepressant is ineffective?
5. What other adjuvant drugs might you consider? In what dose and schedule?
6. How would you integrate behavioral treatments into the pain management strategy?

NOTES

7. If oral drug therapy fails to control his pain, what other strategies could you use? List four in order of preference.

CASE 4. Faculty Guide— Severe Mixed Somatic and Neuropathic Pain

1. Pain type: mixed, somatic and neuropathic
2. Multiple options: current dose of 30 mg q 4 h (180 mg/d) should be increased by 50 percent to 100 percent
 - a. Increase to MSIR 45–60 mg q 4 h scheduled, plus same dose q 1–2 h PRN for breakthrough pain
 - b. Start MSER at 150 q 12 h plus MSIR at 45–60 mg q 1–2 h for breakthrough pain
 - c. Start fentanyl patch: half the oral morphine 24-hour dose ($300 \text{ mg}/2$) = 150 μg fentanyl patch with MSIR 45–60 mg q 1–2 h for breakthrough pain
3. Start at 25 mg of amitriptyline (Elavil), increase by 25 mg every 3 days to target dose of 150 mg; if no response in 7 days at that dose, then discontinue.
4. Start gabapentin (Neurontin) 300 mg daily at bedtime; rapidly escalate the dose up to 2,400 mg (or higher) as needed, in divided doses.
5. Use NSAIDs, alternative antidepressants or anticonvulsants, or steroids.
6. Offer training in relaxation techniques or imagery as soon as possible if the patient is interested.
7. Consider nerve block, acupuncture, nerve stimulator, and wound exploration.

NOTES

Pain Assessment Role Play Exercise | Faculty Guide

1. Review and discuss the **Pain Management** teaching outline.
2. Ask students to form pairs, and distribute the role playing exercise.
3. Students should spend 5 to 7 minutes role playing. The “patient” and “physician” should then independently complete an evaluation form and discuss their impressions of the interview. If there is time, have the students switch partners and change roles so everyone has the opportunity to role play the physician.
4. Debrief the experience with the entire group—good points, bad points, what worked well, what was less effective, what they learned that they would apply in their work, and so forth.
5. You may choose to demonstrate your technique at this type of discussion using the case and choosing one student to play the role of the patient.

Case Blueprint

Purpose of Case: Complete a verbal pain assessment

Training Level: Medical students, postgraduate trainees, or faculty

Simulated patient name: Mr./Mrs. Smith

Diagnosis: Pain, possibly cancer-related

Setting: Hospital room

Time allotted: 7 minutes

NOTES

Patient Profile

Medical History

You are Mr. Smith, a 35-year-old man admitted to the hospital because of severe back pain. You describe the pain as a constant, dull, aching pain over the mid to lower spine. You occasionally have shooting pain down your left leg. You hurt more if you stand. You have had the pain for 3 or 4 weeks, but it became more severe in the last week. It is now a “10” on a 0- to 10-point scale. You have not been able to get out of bed the past 2 days except to go the bathroom. Your left leg feels a little weak, but you have not fallen.

You have been taking Percocet, 2 tablets, off and on when the pain “gets really bad”—about 4 or 5 times a day for the last 2 days. The Percocet takes your pain partially away (to a 7/10) for about an hour; it takes an hour for you to notice that it has started working at all. You hate taking pills, so you are hoping that the physicians can do something to take the pain away. A heating pad has been helpful when the pain gets severe.

You had a localized melanoma removed from your thigh 1 year ago—you were told “we got it all.” You have been working full time since then but have missed the last week of work because of the pain. The pain wakes you at night when you try to turn over in bed. You haven’t had much appetite; you think that’s because of the pain pills.

This experience is very scary for you. You are beginning to wonder if it is “all in your head” or if it could be related to the melanoma.

You are in the hospital to find out what’s going on and to get help with your pain. You would like to have your pain controlled enough so that you can sleep and go back to work. Your pain relief goal is improved mobility.

Social/Family History

You are married and have two children, ages 4 and 8 years. You live with your spouse. You work as a real estate agent. Your parents are alive and well; you have no siblings; you do not use tobacco or drink alcohol.

Setting

You are in a hospital room sitting in a chair next to your bed. You should appear mildly anxious and uncomfortable, rubbing your back and leg frequently.

Task

Your partner, in the role of a physician, will perform a verbal pain assessment.

NOTES

Information for Physician

Medical History

You are a surgeon who has cared for a 35-year-old Mr. Smith admitted to the hospital with increasingly debilitating back pain of unclear etiology. You prescribed Percocet last week when he first called your office about the pain. Today, he called saying his left leg was weak; you arranged for a direct admission to the hospital.

The patient has a history of localized melanoma 1 year ago with no evidence of local-regional or distant metastases.

Setting

You are seeing the patient in the inpatient hospital room. The patient will be seated in a chair.

Task

Complete a verbal pain assessment.

Pain Assessment Learner Assessment Form

Check off the items completed during the pain assessment interview.

- Pain quality
- Pain location
- Pain temporal pattern and duration
- Exacerbating and relieving activities
- Analgesic history
- Other strategies that help
- Impact on sleep and rest
- Emotional state
- Support systems
- Patient asked to name goal of pain relief
- Patient asked what he or she believes pain is from

Overall Impression: Was the physician able to perform an adequate verbal pain assessment?

YES or NO, needs more training

Numeric goal (0-10 scale) or functional goal (such as improved sleep).

NOTES

CHAPTER 3

Dyspnea



Learning Objectives

Attitudes

- Reflect on past experiences managing dyspnea near the end of life.
- Dyspnea is a common end-of-life symptom that has a significant negative impact on quality of life.
- Treating dyspnea with opioids is ethically appropriate if the intent is to relieve suffering.

Knowledge

- Describe at least two disease processes resulting in dyspnea from each of the following categories: (a) obstructive airway diseases; (b) parenchymal lung disease; (c) pleural disease; (d) vascular disease; (e) cardiac disease; (f) chest wall/respiratory muscle disease.
- Describe at least four nondrug treatments for dyspnea.
- Understand the role of opioids and benzodiazepines as drug therapy in managing terminal dyspnea.
- Understand the medical facts and ethical arguments concerning opioid-induced respiratory depression, physician-assisted suicide, and euthanasia in relation to opioids used to treat dyspnea.

Skills

- Demonstrate communication skills in discussing the treatment of dyspnea with patients and families.
- Demonstrate communication skills necessary to take a thorough history from a patient with dyspnea.
- Construct a differential diagnosis for at least three patients with dyspnea.
- Develop an initial treatment plan for at least three patients with dyspnea.
- Demonstrate ability to choose and titrate an initial opioid dose and/or benzodiazepine dose.
- Demonstrate skill at treating dyspnea that is refractory to an initial treatment approach.

NOTES

Pre/Post Test

1. List three causes of dyspnea in the cancer patient related to direct tumor effects:
 - a. _____
 - b. _____
 - c. _____
2. List two causes of dyspnea that are not related to lung, pleural, or cardiac pathology:
 - a. _____
 - b. _____
3. List three nondrug treatments for dyspnea:
 - a. _____
 - b. _____
 - c. _____
4. When using opioids to treat dyspnea, the drug of choice is:

5. Write a prescription for emergency treatment of severe dyspnea in an opioid-naive, 50-year-old dying patient using morphine (dose, schedule, route):
“ _____ ”

Answers

(1) pleural effusion, postobstructive pneumonia, SVC syndrome, (2) anxiety, anemia, (3) relaxation training, fan, open window, (4) morphine, (5) 2–4 mg IV morphine sulfate q 10 min.

Definition

Dyspnea is a subjective sensation of difficulty breathing, an abnormally uncomfortable awareness of breathing. Dyspnea is experienced when there is an imbalance between the perceived need to breathe and the perceived ability to breathe.

Differential Diagnosis

1. **Obstructive airway process**
 - Tracheal obstruction, intrinsic/extrinsic
 - Asthma/chronic obstructive pulmonary disease (COPD)
2. **Lung parenchymal/pleural disease**
 - Diffuse primary or metastatic cancer to lung or pleura
 - Lymphangitic metastases
 - Pneumonia
 - Pneumothorax
 - Pleural effusion, malignant/other
 - Pulmonary drug reaction
 - Radiation pneumonitis
 - Adult respiratory distress syndrome
3. **Vascular disease**
 - Pulmonary embolus
 - Superior vena cava obstruction
 - Pulmonary vascular tumor emboli
4. **Cardiac disease**
 - Congestive heart failure (CHF)
 - Pericardial effusion, malignant/other
 - Arrhythmia
5. **Chest wall/respiratory muscles**
 - Primary neurological disease (eg, amyotrophic lateral sclerosis)
 - Malnutrition
 - Tense ascites

6. Other

- Anxiety
- Anemia

Treatment

Nondrug Therapy

1. **Oxygen**—Nasal cannula better tolerated than mask—especially in the terminal setting; oxygen not always helpful—a therapeutic trial, based on symptom relief, not pulse oximetry, indicated to determine usefulness
2. **Positioning**—Sitting up, leaning forward
3. **Increase air movement**—Open window, bedside fan
4. **Behavioral treatments**—Education, relaxation exercises, distraction, music therapy
5. **Humidified air**, especially for patients with distressing cough
6. **Noninvasive positive pressure ventilation** (mask), often uncomfortable
7. **Pulmonary rehabilitation** for chronic dyspnea (for example, COPD)

Drug Therapy

1. **Opioids:** Particularly helpful when patients experience air hunger and heavy work of breathing. Starting dose depends on current or prior use. For opioid-naïve patients with severe dyspnea, start with 2 to 5 mg IV or subcutaneous (SQ) morphine sulfate (MS), every 5 minutes (IV) or every 15 minutes (SQ) until symptoms improve. Drug of choice is MS (however, all opioids are effective) and can be administered by any route. Slow-release preparations of morphine can be used for chronic dyspnea.

NOTES

2. **Anxiolytics (diazepam [Valium], lorazepam [Ativan], midazolam [Versed]):** Particularly helpful when patients experience anxiety, panic, or a sense of suffocation. For severe dyspnea, give diazepam, 2 to 5 mg, or lorazepam, 1 mg IV every 5 to 10 minutes until symptoms improve.
3. **Cough suppressants:** Opioids act centrally as cough suppressants, as does dextromethorphan, which is chemically related to opioids. Inhaled local anesthetics can also be used to suppress cough: aerosolized lidocaine, start with 2 mL of 2 percent lidocaine (40 mg) q 4 h by inhalation; titrate dose upward as needed. (*Caution: lidocaine use may impair gag reflex, increasing risk of aspiration with eating and drinking, and will impair sense of taste.*)
4. **Steroids:** IV/po dexamethasone/prednisone for bronchospasm, SVC syndrome, or diffuse parenchymal metastases.
5. **Sedatives:** Sedating major tranquilizers (chlorpromazine) or barbiturates (pentobarbital, phenobarbital) may be needed to control dyspnea or anxiety that cannot be managed with opioids and benzodiazepines. (*Chlorpromazine is strongly anticholinergic and, thus, may dry respiratory secretions, which may be helpful [see Anticholinergic agents] or harmful if the results are thick, tenacious secretions that are hard to clear.*)
6. **Anticholinergic agents:** Useful when dyspnea is accompanied by large amounts of thin, watery respiratory secretions (oral and lung). Centrally acting agents: scopolamine, chlorpromazine. Peripherally acting agents: glycopyrrolate. (*Note: Centrally acting agents are more sedating and can cause delirium.*)

Specific Treatments

Treat underlying cause when appropriate (for example, anticoagulation for PE, diuretics for CHF, transfusion for anemia, thoracostomy for pneumothorax, stenting for endobronchial lesions).

Ethical Considerations

Health professionals and the public often mistakenly equate use of opioids to ease dyspnea at the end of life with euthanasia or assisted suicide. Ethically, the use of opioids is appropriate as long as the intent is to relieve distress, rather than shorten life. However, there is no evidence that reasonable and proper use of opioids and anxiolytics results in patients at the end of life “dying sooner.” Understanding the patient’s wishes for end-of-life symptom control and providing good communication with family and other caregivers (eg, nursing staff) regarding the use of these drugs is essential to avoid misunderstanding.

NOTES

Bibliography

- Abernethy AP, Currow DC, Frith P, et al. Randomized, double blind, placebo controlled crossover trial of sustained release morphine for the management of refractory dyspnea. *BMJ*. 2003;327(7414):523–528.
- Bruera E, Schmitz B, Pither J, et al. The frequency and correlates of dyspnea in patients with advanced cancer. *J Pain Symptom Manage*. 2000;19(5):357–362.
- Bruera E, Stoutz N, Velasco-Levra A, et al. Effects of oxygen on dyspnea in hypoxemic terminal cancer patients. *Lancet*. 1993;342(8862):13–14.
- Cherney NI, Portenoy RK. Sedation in the management of refractory symptoms: guidelines for evaluation and treatment. *J Palliat Care*. 1994;10(2):31–38.
- Dalal S, Palat G, Bruera E. Management of dyspnea. In: *Principles and Practice of Palliative Care and Supportive Oncology*. 3rd ed. Berger A, Shuster J, Von Roenn J, eds. Philadelphia, PA: Lippincott-Raven; 2007:277–290.
- Fohr SA. The double effect of pain medication: separating myth from reality. *J Palliat Med*. 1998;1(4):315–328.
- Greene WR, David WH. Titrated intravenous barbiturates in the control of symptoms in patients with terminal cancer. *South Med J*. 1991;84(3):332–337.
- Janssens JP, de Muralt B, Titelion V. Management of dyspnea in severe chronic obstructive pulmonary disease. *J Pain Symptom Manage*. 2000;19(5):378–392.
- Jennings AL, Davies AN, Higgins JP, et al. A systematic review of the use of opioids in the management of dyspnoea. *Thorax*. 2002;57(11):939–944.
- Smith GP II. Terminal sedation as a palliative care: revalidating a right to a good death. *Camb Q Healthc Ethics*. 1998;7(4):382–387.

A Management of Dyspnea Case Study | Faculty Guide (two parts)

Objectives

1. Review the assessment of dyspnea.
2. Develop a differential diagnosis for dyspnea.
3. Develop a patient management plan for dyspnea.
4. Review ethical implications of dyspnea management.

PART I—Teaching Points

- The need for rapid assessment: This patient cannot wait 1 hour for assessment of the effectiveness of any changes. The assessment must be continuous until the patient is more comfortable.
- A pulse oximeter reading will likely not change the therapeutic strategy in this case—as the goal is to relieve the *symptom*, not to treat an oxygen saturation reading.
- Use of oxygen masks is often very disturbing to patients with severe dyspnea, especially in the terminal setting, where oxygen masks should generally be avoided.

Clearly, a rapid assessment for reversible causes is needed.

- Is the oxygen working? Is the oxygen tubing kinked?
- Is there an acute anxiety event in progress?
- Is there a new increase in pain?
- Is there a pneumothorax?

See outline for list of pharmacologic and nonpharmacologic options. Nondrug treatments can include the following:

- Increasing the delivered oxygen
- Opening a window or bringing in a fan
- Bedside relaxation techniques

An appropriate set of drug orders includes the following:

- IV or SQ morphine, 4 mg q 5–15 min, PRN
- IV or sublingual lorazepam, 1 mg q 30 min, PRN

PART II—Teaching Points

The fear of using drug therapy, drugs with the potential for respiratory depression, to ease the distress of dyspnea often leads to inadequate symptom control. Health professionals and the public often mistakenly equate use of drugs to ease dyspnea at the end of life with euthanasia or assisted suicide. Ethically, the use of these drugs is appropriate, as long as the intent is to relieve distress, rather than shorten life. **Note:** **As long as patient or proxy agrees to therapy, there is no justification for withholding symptomatic treatment to a dying patient out of fear of potential respiratory depression. Having said this, it should also be pointed out that there is no evidence that reasonable and proper use of such agents (opioids, anxiolytics) results in patients at the end of life dying sooner.** All major U.S. medical, ethical, and religious organizations recognize the imperative to treat distressing symptoms in dying patients. All of these organizations recognize and accept the concept of “double effect”—so that if the *intent* is to relieve distressing symptoms (and medications are administered and titrated in keeping with reasonable standards of care) and the patient dies, this course of action is considered good medical care, not euthanasia. In contrast, euthanasia is defined as the *intent* to end a patient’s life through an active means. Although this definition seems like a fine distinction, the key concept and distinction are the physician’s intent. Understanding the patient’s wishes for end-of-life symptom control and good communication with family and other caregivers (e.g., nursing staff) regarding how and why drugs to relieve distressing dyspnea are administered is essential to avoid misunderstanding. This shared understanding, the intention to relieve symptoms, not hasten death, should be documented.

NOTES

Part 1

Mr. J. has been on the transplantation service for the past 4 days. He was admitted with end-stage pulmonary fibrosis for evaluation for heart-lung transplant. During the past 3 weeks, he has experienced increasing dyspnea, prompting this admission. On admission, his respiratory rate was 24 to 32 breaths per minute, his pulse was 110 beats per minute, and the pulse oximetry reading was 89 percent saturated with 2 L of oxygen by nasal prongs. An evaluation revealed no reversible causes of dyspnea, and the pulmonary consultant believes the dyspnea is irreversible, caused by the underlying lung disease. The patient was recently determined to be an unsuitable candidate for transplantation and subsequently expressed a wish for *no code* status. Current treatments for the dyspnea include oxygen by nasal prongs and handheld inhalers. He also takes sustained-action morphine, 60 mg q 12 h, for pain, with good relief of back pain from spinal compression fractures (secondary to long-term steroid use) and has an order for 15 mg of immediate-release morphine q 2 h, PRN, for pain.

On the fourth hospital day, while you are making rounds, a nurse interrupts to tell the team that Mr. J. is breathing at a rate of 50 breaths per minute and is very agitated and sitting on the edge of bed gasping for air. The team goes immediately to see Mr. J. and confirms the aforementioned findings. The resident tells the nurse to check pulse oximetry, increase the oxygen to 50 percent by face mask, and call him in 1 hour to report any changes.

QUESTIONS

1. What should be included in your assessment of this acute exacerbation of dyspnea?
2. Is the proposed treatment plan appropriate? If not, why?
3. Suggest an alternative treatment approach; specify nondrug and drug orders (drug, dose, and schedule).

Part 2

A new set of orders is discussed, which includes morphine, 4 mg IV q 10 min, PRN, for dyspnea. However, the intern looks very uncomfortable and finally expresses concern saying, “I understand the medical issues here but it still *feels* like we are doing nothing more than performing euthanasia.”

QUESTION

1. How should you respond to this concern? What arguments will you use? What educational or public policy statements can you use to support the opioid orders?

NOTES



CHAPTER 4

Delirium



Learning Objectives

Attitudes

- Recognize the prevalence of delirium in advanced illness and at the end of life.
- Appreciate the negative impact of delirium on the patient's quality of life.
- Appreciate the distress that delirium causes family members.

Knowledge

- List four clinical features (symptoms, signs) of delirium.
- Distinguish between delirium and dementia.
- Describe the differences between a hypoactive and hyperactive-agitated delirium.
- Describe at least two causes of delirium from each of the following categories: (a) metabolic; (b) drugs; (c) central nervous system (CNS) pathology; (d) drug withdrawal.
- Understand key diagnostics that may be helpful in determining cause of delirium (for example, Na, Ca⁺⁺).
- Understand when it is appropriate *not* to pursue the underlying cause of delirium.
- Describe at least three nonpharmacologic measures to treat delirium.
- Describe indications for initiating pharmacologic management of delirium.
- List appropriate medications and initial dosing for the management of delirium.

Skills

- Demonstrate the ability to conduct a structured assessment for delirium (for example, Confusion Assessment Method [CAM]), including cognitive testing (for example, mini-mental state examination [MMSE]).
- Construct a differential diagnosis for at least three patients with delirium.
- Develop an initial treatment plan for at least three patients with delirium.
- Demonstrate the ability to choose and titrate an initial drug management.
- Demonstrate skill at treating delirium that is refractory to an initial treatment approach.
- Demonstrate communication skills to educate and reassure family members of patients with delirium.

Pre/Post Test

1. List four cardinal features of delirium:
 - a. _____
 - b. _____
 - c. _____
 - d. _____
2. List three findings from the history and mental status examination that distinguish delirium from dementia:
 - a. _____
 - b. _____
 - c. _____
3. List three common metabolic causes for delirium:
 - a. _____
 - b. _____
 - c. _____
4. List three common classes of drugs that can cause delirium:
 - a. _____
 - b. _____
 - c. _____
5. List three nondrug measures that are helpful with a delirious patient:
 - a. _____
 - b. _____
 - c. _____
6. List the two classes of drugs most useful in treating delirium:
 - a. _____
 - b. _____
7. Write a prescription for emergency treatment of severe delirium (drug, dose, schedule, route):
“ _____ ”

Answers

(1) disturbance of consciousness with reduced ability to focus or sustain attention, acute onset or fluctuates during course of day, change in cognition or perceptual disturbance, typically has underlying medical cause, (2) dementia: long history, normal state of arousal, primary issue is loss of memory, (3) elevated calcium level, low glucose level, renal failure, (4) benzodiazepines, opioids, anticholinergics, (5) frequent reminders of date, lights on, family at bedside, (6) neuroleptics, benzodiazepines, (7) haloperidol (Haldol), 2 mg po q 8 h and 1 mg po 1mg IV q 1 hr PRN.

Delirium at the End of Life

Definition

Delirium (also known as acute confusional state) refers to an *altered level of consciousness* (ie, state of arousal) with associated features of reduced ability to shift, focus, or sustain attention and an acute onset or fluctuating course throughout the day. Delirium typically has an underlying medical cause. Other common features include perceptual disturbances (hallucinations and/or delusions), disorientation, incoherent speech, and altered sleep-wake cycle.

- Delirium occurs to some degree in virtually all patients before death.
- The cause is often multifactorial; an exact cause cannot be established in 40 percent or more of patients.
- Unlike delirium in other situations (acute illness in geriatric patients, for example) delirium in patients close to death is often not reversible, although even in populations of palliative care patients, up to 50 percent have reversible delirium.
- Delirium manifests as *agitated/hyperactive delirium*, with the person climbing out of bed, pulling out IV lines, picking at air, or mumbling of speech, or *hypoactive delirium*, in which the person is quiet and very sleepy and has mumbling speech.
- Delirium is frequently underrecognized and, therefore, undertreated; hypoactive delirium may be mistaken for depression.
- Hyperactive and hypoactive delirium are considerable sources of distress for family members witnessing it.

Differential Diagnosis

- Metabolic—hypoxia, hypercalcemia, hyponatremia or hypernatremia, hypoglycemia, liver or renal failure, dehydration
- CNS pathology—metastases, infarction, bleeding, infection, seizures
- Drug withdrawal—alcohol, benzodiazepines, barbiturates
- Drug toxicity—benzodiazepines, anticholinergics, opioids, steroids, illicit drugs, alcohol
- Other—systemic infections, fever, heart failure, imminent death, urinary retention or constipation, sleep deprivation, hyperviscosity
- Older age, higher severity of illness, and pain are risk factors for developing delirium.

Assessment

- Perform a structured assessment for delirium, using a validated tool (eg, MMSE; CAM) and/or structured cognitive testing (for example, list days of the week backward, serial 3s, 3-step command; clock draw).
- Distinguish between delirium and dementia. Dementia refers to a loss of intellectual function with diminished memory, thinking, and judgment (also called executive functions).
- Determine if the patient is in danger of harming self or others and if the cognitive dysfunction is distressing to the patient or family.
- When clinically appropriate, a complete evaluation includes examination of blood, urine, spinal fluid samples, and radiographic studies to evaluate for metabolic causes, infection, or CNS pathology.
- Evaluate first for the most easily reversible and common causes: hypoxia, drug effects, metabolic problems such as hypoglycemia, hypoxia, infections, and seizures.
- Reassess the patient's mental status frequently (at least daily).

NOTES

Mini-Mental State Examination (MMSE)

A score of 24 and above is considered normal.

Orientation		
What is the (year) (season) (day) (date) (month)?	1 point for each correct	(5)
Where are we (state) (country) (town) (hospital) (floor)?	1 point for each correct	(5)
Registration		
Name three objects slowly, then ask the patient to repeat them.	1 point for each correct	(3)
Attention and calculation		
Serial 7s. Stop after five answers. Or, spell "world" backward.	1 point for each number or letter correct	(5)
Recall		
Ask for the three objects repeated above.	1 point for each correct	(3)
Language		
Name a pencil and a watch.	1 point for each correct	(2)
Repeat "no ifs, ands, or buts."	1 point	(1)
Follow three-stage command: <i>"Take a paper in your hand, fold it in half, and put it on the floor."</i>	1 point for each correct	(3)
Read and obey: CLOSE YOUR EYES	1 point	(1)
Write a sentence.	1 point	(1)
Ask the patient to copy a pair of intersecting pentagons.	1 point if figure has 10 corners and two intersecting lines.	(1)
Total		(30)

Confusion Assessment Method (CAM)

The CAM has been validated and correlates well with the MMSE. The CAM includes two parts: a confusion assessment instrument that screens for overall cognitive impairment, and a diagnostic algorithm that include the features that distinguish delirium or reversible confusion from other types of cognitive impairment such as dementia.

The CAM assessment and diagnostic algorithm can be accessed at http://elderlife.med.yale.edu/pdf/The_Confusion_Assessment_Method.pdf

NOTES

Treatment

Clarify the goals and expectations of care with the patient and/or family.

If possible and consistent with patient and family goals, the first step in treating delirium is to attempt to identify and correct underlying cause.

Review current medications. Consider discontinuing suspect medications (drugs associated with delirium that were recently started) or switching to less high-risk agents.

NOTE: *Opioids required for management of pain or dyspnea should **not** be discontinued abruptly. Consider switching to a different opioid or lowering the dose to see if the delirium improves, while closely monitoring the relief of pain or dyspnea.*

Nonpharmacologic Supportive Therapy

- Frequent reminders of time and date
- A quiet, well-lit room, calming music, night light
- Continuous presence of a family member or health professional to help allay fears and provide patient support
- Physical restraints rarely necessary; used only as a brief temporizing measure while instituting nondrug and drug treatments
- Rehydration (may be oral): In selected cases, correction of dehydration may improve delirium, especially when the delirium is caused by accumulation of medication metabolites.

Pharmacologic Therapy

A decision should be made as to whether the primary goal of therapy is to *clear the sensorium* (reverse or ameliorate the delirium) or to *provide symptomatic relief* for distress and agitation associated with delirium. Relatively nonsedating neuroleptics, such as haloperidol, may help clear the sensorium. When the delirium is thought to be refractory to such efforts or when such efforts have not been successful, symptomatic relief with a sedating neuroleptic (eg, chlorpromazine) and anxiolytic agents is often appropriate.

NEUROLEPTICS (*Caution when treating patients with active seizure disorders*)

Typical

- Haloperidol (Haldol), 0.5–2 mg po, IV, subcutaneously (SQ; SQ infusion, start at 1 mg/h)
- Chlorpromazine (Thorazine), 12.5–50 mg po, PR, IV, IM

Atypical

- Olanzapine (Zyprexa), 2.5–5 mg po/sublingual (SL) daily
- Risperidone (Risperdal), 0.25–0.5 mg po/SL BID
- Quetiapine (Seroquel), 12.5–25 mg po BID

Benzodiazepines

- Lorazepam (Ativan), 0.5–2.0 mg po, IV
- Diazepam (Valium), 2–10 mg po, IV, IM
- Midazolam (Versed), 2–10 mg IV, SQ (SQ infusion, start at 1 mg/h)

Starting treatment: Neuroleptics should be used as first-line drugs. Benzodiazepines are high-risk medications for causing delirium and may increase agitation in some patients. There are no current data that newer antipsychotics are more effective at decreasing the length or severity of delirium compared with older drugs, nor have atypical antipsychotics been shown to have fewer extrapyramidal side effects in this population. If trying to clear the sensorium, consider using haloperidol, 1–2 mg po or SQ q 6 h with 1–2 mg q 1 h PRN; titrate upward as needed (NOTE: contraindicated in Parkinson disease; watch for extrapyramidal side effects.) More sedating neuroleptics, such as chlorpromazine, may be used when sedation is indicated. Starting dose: 25–50 mg q 6 h po, rectally, IM with 25 mg q 1 h PRN; titrate upward as needed.

Benzodiazepines will not help clear the sensorium (and often worsen delirium). They are useful in this setting primarily for their sedating effects in patients with refractory agitation.

NOTES

Bibliography

- Breitbart W, Marotta R, Platt MM, et al. A double blind trial of haloperidol, chlorpromazine, and lorazepam in the treatment of delirium in hospitalized AIDS patients. *Am J Psychiatry*. 1996;153(2):231–237.
- Breitbart W, Gibson C, Tremblay A. The delirium experience: delirium recall and delirium-related distress in hospitalized patients with cancer, their spouses/caregivers, and their nurses. *Psychosomatics*. 2002;43(3):183–194.
- Casarett DJ, Inouye SK. Diagnosis and management of delirium near the end of life. *Ann Intern Med*. 2001;135(1):32–40.
- Cherny NI, Portenoy RK. Sedation in the management of refractory symptoms: guidelines for evaluation and treatment. *J Palliat Care*. 1994;10(2):31–38.
- Inouye S, van Dyck C, Alessi C, et al. Clarifying confusion: the Confusion Assessment Method. *Ann Intern Med*. 1990;113(12):941–948.
- Jackson KC, Lipman AG. Drug therapy for delirium in terminally ill patients. *Cochrane Database Syst Rev*. 2004;(2):CD004770.
- Lawlor PG, Gagnon B, Mancini IL, et al. Occurrence, causes, and outcome of delirium in patients with advanced cancer: a prospective study. *Arch Intern Med*. 2000;160(6):786–794.
- Shuster J. Cognitive disorders: delirium and dementia: In: Berger A, Shuster J, Von Roenn J, eds. *Principles and Practices of Palliative Care and Supportive Oncology*. 3rd ed. Philadelphia, PA: Lippincott-Raven; 2007:435–443.
- Stedeford A, Regnard C. Confusional states in advanced cancer: a flow diagram. *Palliat Med*. 1991;5(3):256–261.
- Sykes N, Thorns A. Sedative use in the last week of life and the implications for end-of-life decision making. *Arch Intern Med*. 2003;163(3):341–344.

NOTES

Management of Delirium

Case Study | Faculty Guide

Objectives

1. Review the major components of the delirium assessment.
2. Correctly administer a delirium assessment scale.
3. Develop a differential diagnosis for delirium.
4. Develop a patient management plan for delirium.

Teaching Points

- “Confusion” is a common but imprecise term that can include delirium, dementia, hallucinations, delusions, and other conditions.
- Nighttime cognitive changes (“sundowning”) are common in hospitalized patients, especially elderly patients and patients with fever or metabolic disturbances, borderline cognitive function, or patients receiving psychoactive medications, particularly benzodiazepines.
- A diagnosis and appropriate treatment cannot be established without an appropriate assessment. An appropriate assessment would include bedside cognitive testing (for example, MMSE), a basic neurologic examination, review of recent medication changes, and assessment for evidence of underlying causes (for example, hypoxia, infection). Further workup is dependent on the clinical situation and the patient goals (for example, evaluating potential metabolic change only if treatment would be instituted).
- Discontinuing morphine will lead to opioid withdrawal and is not appropriate because no assessment has been done. In addition, the patient is left with untreated pain, which is a risk factor for delirium. Lorazepam (Ativan) will cause temporary sedation but also has the potential for worsening cognitive deficits and potentiating the CNS depressant effects of other psychoactive drugs.

- Treatment options include the following:
 - i. Reorientation and leaving a light on
 - ii. Use of a major tranquilizer such as haloperidol PRN, for disturbing hallucinations or concern about physical harm
 - iii. Avoidance of benzodiazepines; continuation of opioids

Case

Mr. J. is at postoperative day 4 following an open reduction and internal fixation of the right hip for a pathologic fracture from metastatic lung cancer. He is now breathing comfortably with 3 L oxygen and continues to receive 30 mg of extended-release morphine q 12 h. He has been receiving the extended-release morphine for 2 weeks with no side effects, except constipation. Tonight, the night before planned discharge to home with home hospice care, he becomes “confused.” The house officer is called at 2:00 am and orders 1.0 mg of IV lorazepam and discontinues the morphine.

QUESTIONS

1. Describe an appropriate initial assessment for this patient.
2. Develop a rank-ordered differential diagnosis for this patient.
3. Do you agree with the stated treatment plan? If not, design a new plan.

NOTES



CHAPTER 5

Depression

“The opposite of depression is not happiness but vitality...”

—Andrew Solomon, *The Noonday Demon. An Atlas of Depression*

Learning Objectives

Attitudes

- Realize that a major depression is not a normal aspect in patients near the end of life.
- Reflect on personal attitudes about the meaning of depression in caring for a patient with a terminal illness.

Knowledge

- Describe the diagnostic criteria for major depression and how they are applied in terminal illness.
- List at least three risk factors for major depression.
- Describe the differences between major depression and anticipatory grief.
- List at least two causes of depressive symptoms from each of the following categories: (a) medications or other drugs; (b) central nervous system (CNS) pathology; (c) general medical conditions.
- Describe how to assess and manage a patient with suicidal ideation.
- Describe how to determine whether fatigue is due to physical illness or depression.
- Describe appropriate medication options for depression.
- Describe when and how to start a stimulant in a depressed patient.
- Describe how to select, start, and adjust at least two nonstimulant antidepressants.
- Describe the indications for psychiatric consultation.

Skills

- Demonstrate communication skills necessary to obtain a thorough history from a patient who may be depressed.
- Construct a differential diagnosis for at least three patients who may be depressed.
- Demonstrate skill at ordering diagnostics to determine potential organic causes of depressive symptoms.
- Develop an initial treatment plan for at least three patients who exhibit emotional distress at the end of life.
- Demonstrate ability to choose and titrate an initial medication plan using a stimulant.
- Demonstrate ability to choose and titrate an initial medication plan using a nonstimulant antidepressant.
- Explain what to do if the first medication trial is ineffective.

NOTES

Pre/Post Test

1. List seven signs/symptoms that define the diagnostic criteria for major depression (in addition to depressed mood or anhedonia):
 - a. _____
 - b. _____
 - c. _____
 - d. _____
 - e. _____
 - f. _____
 - g. _____
2. List at least three findings from the history and mental status examination that distinguish depression from anticipatory grief:
 - a. _____
 - b. _____
 - c. _____
3. List three drugs that can cause depression:
 - a. _____
 - b. _____
 - c. _____
4. List three medical conditions that can cause depression:
 - a. _____
 - b. _____
 - c. _____
5. List the two classes of drugs most useful in treating depression at the end of life:
 - a. _____
 - b. _____
6. What treatments other than drugs are indicated for depression?
 - a. _____
 - b. _____

Answers

(1) sleep disruption, weight loss or change in appetite, psychomotor slowing or agitation, fatigue, or low energy, feelings of worthlessness or excessive guilt, impaired thinking or concentration, suicidal thoughts, (2) noncathartic crying, anhedonia, loss of hope and meaning, (3) alcohol, opiates, antiandrogenic agents, others, (4) brain tumors, hypothyroidism, adrenal failure, others, (5) psychostimulants, antidepressants, (6) supportive therapy, family education.

Depression at the End of Life

Depression in the Setting of a Terminal Illness

- Depression is not a “normal” response to terminal illness, but anticipatory grief is.
- About 10 to 25 percent of patients with terminal illness meet the criteria for a depressive disorder, depending on the study and criteria used.
- Depression is a major risk factor for desire to hasten death (even more than pain), and up to 59 percent of terminally ill patients who request assisted suicide are depressed.
- The strongest risk factor for depression is a history of depression or other mood disorder (such as bipolar disorder). Others include younger age, poor social supports, pain, and poor functional status.
- Further research is needed to improve the diagnostic criteria for depression in terminal illness; however, the multimodal treatments outlined herein are generally effective at alleviating suffering.

Diagnosis

Depression (also called major or clinical depression) refers to a persistently depressed mood, or anhedonia (loss of interest or pleasure in usual activities), that lasts for 2 weeks or more and is accompanied by at least four of the following seven symptoms:

- Sleep disruption (insomnia or hypersomnia)
- Weight loss or change in appetite
- Psychomotor slowing or agitation
- Fatigue or loss of energy
- Feelings of worthlessness or excessive guilt
- Diminished ability to think or concentrate (or indecisiveness)
- Recurrent thoughts of death (not just fear of dying) or suicidal ideation

Irritable mood is already accepted as an equivalent of depressed mood in children and adolescents and will most likely be accepted for adults in the near future, so it should be counted toward the diagnosis in the end-of-life setting. Because treating depression is low risk and greatly improves quality of life, count any sign or symptom toward establishing the diagnosis in patients with terminal illness, unless it is clearly attributable only to the underlying disease or side effects of treatment. If in doubt about whether the cause of a given symptom is medical or psychiatric and for cases on the threshold of meeting diagnostic criteria, lean toward diagnosing depression when other risk factors exist (see later text).

NOTES

Differential Diagnosis

- **Delirium**—especially hypoactive delirium in which patients are passive and withdrawn but have deficits evident in the cognitive exam (see Chapter 4, Delirium). Pearl: An abnormal clock drawing shows delirium or dementia, not depression.
- **Dementia**—pervasive loss of intellectual function (often memory more than attention or orientation evident in the exam) that is long-standing and progressive
- **Drug effects**—opioids, corticosteroids, interferon, antiandrogenic agents, barbiturates, benzodiazepines, tyrosine kinase inhibitors, alcohol or other illicit drugs, beta-blockers, and certain chemotherapies
- **CNS pathology**—brain tumors or metastases (especially in the temporal lobe), brain radiation (especially whole brain), stroke, infection, seizures, sleep apnea
- **General medical conditions**—thyroid dysfunction, vitamin B₁₂ or folate deficiency, low testosterone level, adrenal failure, electrolyte abnormalities (especially sodium), liver failure, hypercalcemia, hyperglycemia, myocardial infarction, infections
- **Anticipatory grief**—the normal response to loss and dying. Patients who are grieving usually experience crying as cathartic (“getting it off my chest”), can still enjoy usual activities and find meaning in relationships, and have hope for the future. Depressed patients experience crying as draining and purposeless, are anhedonic (have no pleasure in anything), and may lose hope and meaning (as also in demoralization).
- **Demoralization**—a syndrome in which patients can enjoy the present moment (that is, are not anhedonic as in depression), but lose hope for improvement or recovery from illness. Demoralized patients report pronounced meaninglessness or loss of purpose, feel very helpless or stuck in their predicament, and can develop suicidal thoughts and plans.

Assessment

- Perform a history and physical examination with detailed mental status examination, using a cognitive assessment tool (Mini-Mental State Examination or clock drawing test) to rule out delirium or dementia.
 - Observe for flat affect or psychomotor slowing (seen in depression), inquire about cathartic crying episodes (seen in grief), and ask about pronounced hopelessness and helplessness (demoralization).
 - Characterize pattern of fatigue. In illness-related fatigue, mood and energy are better in the morning, improve with napping, and worsen late in the day. In depression, mood and energy are down in the morning and stay fixed or improve during the day.
 - Obtain collateral information from family and caregivers because depressed patients may lose self-awareness and underreport signs and symptoms.
- Self-report tools are imperfect, but major depression is suggested by a HADS (Hospital Anxiety and Depression Scale) score of 19 or 20 or higher; an EDS (Edinburgh Depression Scale) score of 13 or higher; or a PHQ-9 (Patient Health Questionnaire) score of 15 or higher.
- Determine if the patient has suicidal ideation with an active intention or plan; if threat of self-harm seems imminent, order a sitter for safety and request psychiatric consultation.
 - No sitter is needed for passive suicidal thoughts without intention or viable plan, but psychiatric consultation is helpful to further evaluate requests for euthanasia or physician-assisted suicide.
- Evaluate for fixed and modifiable causes of depressive symptoms (listed earlier; drug effects, CNS pathology, general medical conditions).
- Assess for (and treat) comorbid symptoms that may be worsening mood (pain, nausea, constipation, dyspnea, and so on).
- Evaluate for depression versus demoralization versus grief. In addition to presence of anhedonia and other cardinal symptoms of depression, the following can help clarify the diagnosis:

NOTES

Indications for Psychiatric Consultation

- Suicidal ideation with active intention or plan to harm self
- Requests for hastened death or physician-assisted suicide
- Altered mental status, agitation, or obvious dementia
- Extreme withdrawal or passive refusal to participate in care
- Evaluation of decision-making capacity when it is in doubt
- Preexisting history of major mental illness (such as schizophrenia, bipolar disorder, treatment-resistant major depression, or mental retardation or developmental disorder)
- Known or suspected substance abuse and/or personality disorder
- Provocative, demanding, aggressive, hostile, or otherwise difficult behavior
- Overly anxious, dependent, or odd behavior
- Management of psychotropic polypharmacy
- Treatment-resistant insomnia, fatigue, nausea, or pain, especially when psychosocial distress may be a contributing factor
- Nonresponse to standard interventions for depression and anxiety
- When patient and family are in conflict with the medical or surgical team

Treatment

All patients with emotional distress at the end of life require comprehensive palliative care that controls physical symptoms and addresses psychosocial concerns using a multidisciplinary approach (medical, surgical, social work, chaplaincy, nursing, palliative medicine consultants or hospice, and psychiatry or other support services as indicated). In addition, the primary medical or surgical team should oversee treatment as follows:

Anticipatory Grief

- Treatment is supportive and problem-oriented.
- Maintain effective communication by listening empathically and encouraging discussion of end-of-life issues (prognosis, code status, hospice plans, fears about suffering, final arrangements, parenting concerns, family distress, spiritual or existential distress, leaving a legacy, making meaning, and so on).
- Do not try to reassure patients who are fearful of death or suffering because they can feel dismissed. Rather, listen to them, acknowledge that their concerns are real and understandable, and tell them that you will not abandon them and will do everything possible to alleviate their suffering.
- Antidepressants are not indicated for grief reactions but can be used to mitigate distressing symptoms such as insomnia, anxiety, irritability, or excessive tearfulness (see later text).
- Stimulants help illness-related fatigue and can improve mood by increasing energy and activity level.
- Benzodiazepines can help situational anxiety and/or insomnia but can affect mental status in vulnerable patients (for example, elderly patients).
- Non-habit-forming sleeping agents such as trazodone or mirtazapine can be used instead of or in judicious combination with benzodiazepines for insomnia.

NOTES

Major Depression

- Treatment requires a combination of stimulants and/or antidepressants, psychotherapy for the patient, and education and support for the family or caregiver.
- Enlist social work, psychology, and/or psychiatry to provide psychotherapy and family education and support.
- Give one to two medication trials and, if no response, consult psychiatry.
- Start with a stimulant if patient's life expectancy is less than 1 or 2 months; otherwise start with an antidepressant.
- It is safe to augment antidepressants with stimulants and vice versa, but start one at a time so as to monitor effects and side effects.
- **NOTE:** Opioids and corticosteroids can improve mood in depression at the end of life. When starting these drugs for physical symptoms, assess the impact on mood for 2 to 4 days before adding a stimulant or an antidepressant.
- **NOTE:** High-dose opioids can cause medication-induced depression that is rapidly reversed with stimulants; high-dose steroids can cause anxiety, insomnia, irritability, and even mania that are best controlled with neuroleptics (see dosing information in Chapter 4, Delirium).

STIMULANTS

- Act rapidly (24–48 hours); counter opioid-related sedation, fatigue, and cognitive dysfunction; and may have adjuvant analgesic activity
- Only major contraindications are uncontrolled seizures, ongoing mental status change, severe hypertension, or life-threatening arrhythmias; safe for patients with a seizure disorder controlled with antiepileptic drugs and stable cardiac conditions
- Common side effects: anxiety, tremors, palpitations, and irritability; therefore, control of significant anxiety or irritability needed before adding a stimulant
- Methylphenidate (Ritalin) titration schedule:

Day 1	5 mg IR in morning
Day 2	5 mg IR in morning, 2.5 mg at noon
Day 3	5 mg IR in morning, 5 mg at noon
Day 4	10 mg IR morning, 5 mg at noon
Days 5–7	5–10 mg IR twice daily, as tolerated (adjust for any emerging side effects)
Week 2	continue if effective, or increase further to: 20 mg SR in morning, plus 5–10 mg IR twice daily as needed add antidepressant if needed

- Some patients may need a late afternoon “booster” dose of 5 to 10 mg IR.
- For anxious, frail, or elderly patients, start titration schedule at 2.5 mg in morning and increase daily in 2.5 mg increments to desired effect.

ANTIDEPRESSANTS

- All equally effective for mood; therefore, select by desired side effect profile.
- Takes 2 weeks for initial response and 4 weeks for peak effect at a given dose.
- If patient shows partial response at 1 month, increase dose or augment with a stimulant for residual fatigue.
- If patient shows little or no response at 1 month, switch to a second agent, or try a stimulant for prominent fatigue.

Selective serotonin reuptake inhibitors (SSRIs)

- Not sedating; especially good for comorbid irritability or tearfulness

NOTES

- Main side effects are gastrointestinal (gas, nausea, discomfort, diarrhea); occasionally cause headache, or paradoxical anxiety or drowsiness
 - i. Citalopram (Celexa) 10 mg nightly for 4 nights, then 20 mg nightly; maximum, 60 mg
 - ii. Sertraline (Zoloft) 25–50 mg daily for 1 week, then 50–100 mg daily; maximum, 200 mg
- For elderly people, use lowest available starting dose, increase more slowly

Mirtazapine (Remeron)

- Sedating, also improves appetite and nausea
- Side effects are excessive sedation, falls, and weight gain; anticholinergic, so avoid with ileus or urinary retention
- For adults, start 7.5 mg for 1 or 2 nights, then 15 mg nightly; may increase to 30 mg after 2 to 4 weeks; maximum, 45 mg
 - i. For elderly, start 3.75 to 7.5 mg nightly, monitor for sedation; maximum, 15 mg

SLEEPING AGENTS

Lorazepam (Ativan)	0.5–2 mg po, IV (can worsen delirium)
Trazodone	25–100 mg po
Mirtazapine	(Remeron)7.5–30 mg po or sublingual (dissolving tablet)
Zolpidem (Ambien)	5–20 mg po (can cause dreams, confusion, sleep walking)

Bibliography

American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders: DSM-IV-TR*. 4th ed. Washington, DC: American Psychiatric Association; 2000.

Block SD. Psychological issues in end-of-life care. *J Palliat Med*. 2006;9(3):751–772.

Brown ES, Chamberlain W, Dhanani N, et al. An open-label trial of olanzapine for corticosteroid-induced mood symptoms. *J Affect Disord*. 2004;83(2–3):277–281.

Breitbart W, Alici Y. Pharmacologic treatment options for cancer-related fatigue: current state of clinical research. *Clin J Oncol Nurs*. 2008;12(5 suppl):27–36.

Candy M, Jones L, Williams R, et al. Psychostimulants for depression. *Cochrane Database Syst Rev*. 2008;(2):CD006722.

Cankurtaran ES, Ozalp E, Soygur H, et al. Mirtazapine improves sleep and lowers anxiety and depression in cancer patients: superiority over imipramine. *Support Care Cancer*. 2008;16(11):1291–1298.

Lloyd-Williams M, Reeve J, Kissane D. Distress in palliative care patients: developing patient-centred approaches to clinical management. *Eur J Cancer*. 2008;44(8):1133–1138.

Miovic M, Block S. Psychiatric disorders in advanced cancer. *Cancer*. 2007;110(8):1665–1676.

Qaseem A, Snow V, Shekelle P, et al. Evidence-based interventions to improve the palliative care of pain, dyspnea, and depression at the end of life: a clinical practice guideline from the American College of Physicians. *Ann Intern Med*. 2008;148(2):141–146.

NOTES

Case Study | Faculty Guide

Objectives

1. Review the major components of the depression assessment.
2. Develop a differential diagnosis for depression.
3. Develop a patient management plan for depression.
4. Discuss how to assess and manage fatigue in terminal illness.

Teaching Points

- The colloquial use of the word “depressed” is imprecise and can mean anticipatory grief, demoralization, illness-related physical fatigue, general emotional distress, or major depression.
- Family and caregiver observations are important because depressed patients may lose self-awareness and underreport their degree of distress and dysfunction.
- Whole-brain radiation can cause fatigue and is a risk factor for depression. Fatigue due to brain radiation is less in the morning (because the patient has slept), worsens during the day, may be alleviated by napping, and often is very debilitating by evening. This pattern is due to cognitive overload developing the longer the patient remains awake and has to process information. Consequently, mood is also better in the morning but declines during the day as the patient tires. In contrast, in depression, mood and energy are uniformly low throughout the day or are actually worse in the morning and improve by evening (because the longer the patient is awake, the more that stimulatory neurotransmitters and external activities can wake up the frontal cortex).
- Depressive crying is felt as draining, repetitive, and unprovoked by any clear trigger and does not help ventilate feelings. Crying due to grief is felt as ventilatory and relieving, is clearly linked to specific reminders of loss, and helps people come to terms with their situation.

- Anhedonia (loss of pleasure in usual activities or relationships) is very indicative of depression. Anhedonic patients have the physical energy to engage in some activities and to relate to people but lack the desire and motivation to do so.
- Treatment options include the following:
 - Starting an antidepressant (SSRI or mirtazapine)
 - Workup for possible medical causes of depression and fatigue
 - Psychotherapy to help patient process feelings about grief, loss, and death
 - Education and supportive therapy for the family
 - Consider increasing methylphenidate; consider steroids if indicated

Case

Mr. C. has lung cancer, metastatic to the brain and has had whole-brain radiation, with a prognosis of 3 to 6 months to live. His breathing is now comfortable with 2 L of oxygen, and his pain is controlled with oxycodone, extended-release, 60 mg every 8 hours. His family says he is depressed, but he says he’s just “tired of being tired.” He closes his eyes and is withdrawn while his family speaks about him but has intact cognitive exam results on formal testing. When you ask about his mood, he breaks down crying and says “Doc, what’s the point? Can’t you just give me something to go to sleep?” His family reports he has been uncharacteristically irritable, tearful, and socially withdrawn and ruminates on death. He doesn’t seem to get pleasure out of anything anymore. His radiation oncologist started methylphenidate, 20 mg SR, for postradiation fatigue, with improved alertness and appetite. However, the patient says “What difference does it make?”

QUESTIONS

1. Describe an appropriate initial assessment for this patient.
2. Describe questions and history that could help establish whether the diagnosis is major depression, demoralization, grief, illness-related fatigue, or a mixture of these.
3. Do you agree with the stated treatment plan? If not, design a new plan.

NOTES

CHAPTER 6

Nausea



Learning Objectives

Attitudes

- Reflect on past good and bad experiences managing nausea and vomiting.
- Nausea is a common symptom reported by patients at the end of life. Nausea has a significant negative impact on quality of life.

Knowledge

- Understand the role of the cerebral chemoreceptor trigger zone (CTZ) and vomiting center in the mediation of nausea and vomiting.
- Describe three anatomic sites that send afferent input to the medullary vomiting center.
- Know at least two causes of nausea and vomiting from each of the following categories: gastrointestinal, central nervous system (CNS), drugs, metabolic, and psychological.
- Identify one drug, and understand its mechanism of action and relative cost from each of the following classes: (a) dopamine antagonist, (b) serotonin antagonist, (c) glucocorticoid, (d) benzodiazepine, (e) cannabinoid, (f) antihistamine, (g) neurokinin-1 antagonist.
- Understand the role of behavioral treatments for nausea.

Skills

- Demonstrate communications skills necessary to take a thorough history from a patient with nausea.
- Construct a differential diagnosis for at least three patients with nausea.
- Develop an initial treatment plan for at least three patients with nausea.
- Demonstrate skill at treating nausea that is refractory to an initial treatment approach.
- Understand resources for managing nausea refractory to standard pharmacologic management.
- Prescribe antiemetics in a cost-effective manner.

Nausea and Vomiting

Pre/Post Test

1. List three anatomic sites that send afferent input to the medullary vomiting center:
 - a. _____
 - b. _____
 - c. _____
2. List four gastrointestinal causes of nausea:
 - a. _____
 - b. _____
 - c. _____
 - d. _____
3. List the most appropriate class of antiemetic drugs to use in the following conditions:
 - a. elevated intracranial pressure: _____
 - b. gastric stasis: _____
 - c. hypercalcemia: _____
 - d. middle ear infection: _____
4. List one drug that can be used as a continuous infusion for refractory nausea:
 - a. _____

Answers

(1) frontal cortex, CTZ, vagus nerve, (2) gastritis, bowel obstruction, ulcer, gastric stasis, (3) steroid, promotility drug, dopamine antagonist, antihistamine, (4) metoclopramide or chlorpromazine.

Nausea and Vomiting

Mechanism of Vomiting

Vomiting Center: Control center in medulla for coordinating the *efferent output* of vomiting motor sequence (vomiting reflex).

Sources of *afferent input* to the vomiting center:

- **Chemoreceptor trigger zone (CTZ)**—Entry point for emetogenic blood or cerebrospinal fluid-borne substances; located in the area postrema outside the BBB (morphine, hypercalcemia, uremia)
- **Cerebral cortex**—Limbic system (for example, anxiety, anticipatory nausea)
- **Visceral afferent**—(vagal) stimulation—Pharynx, gastrointestinal (GI) tract (mechanoreceptors, chemoreceptors, responding to inflammation)
- **Midbrain ICP receptors**—For example, raised intracranial pressure
- **Vestibular system**—For example, neurotoxins, morphine, infections, tumor

Differential Diagnosis

Gastrointestinal—Mechanical obstruction (constipation, intrinsic/extrinsic obstruction), dysmotility (gastric and bowel stasis), squashed stomach syndrome (compression of stomach, usually by enlarged liver), inflammation (GI infection, gastroesophageal reflux disease, gastritis, abdominal carcinomatosis, acute effect of abdominal radiation or chemotherapy)

CNS—Elevated ICP, posterior fossa tumors/bleeding, infection, or neoplastic meningitis

Drugs—Opioids, chemotherapy, selective serotonin reuptake inhibitors, nonsteroidal antiinflammatory drugs, antibiotics, iron

Metabolic—Hypercalcemia, liver failure, renal failure

Psychological—Anxiety, pain, conditioned response (such as anticipatory nausea/vomiting)

1. Nausea via stimulation of CTZ
2. Nausea via gastric/gut slowing
3. Nausea via stimulation of vestibular system
4. Nausea via stimulation of gut chemoreceptors and vagal afferents

NOTES

Treatment

Nondrug Therapy

- **Behavioral treatments**—Relaxation, imagery, distraction, music
- **Nasogastric drainage**—Indicated mainly for acute management of gastric stasis/obstruction or bowel obstruction refractory to conservative management
- **Percutaneous gastrostomy**—Indicated for long-term decompression for gastric stasis/obstruction or bowel obstruction refractory to conservative management
- **Fluid restriction**—Patients with GI obstruction may benefit from restriction of oral fluids and/or discontinuing IV fluids to decrease GI fluid output and vagal stimulation.

Drug Therapy

There are many antiemetics to choose from. Although often used in a trial-and-error manner, certain disorders respond best to a drug from a specific drug class. These include the following:

Movement-related nausea	Antihistamine
Anxiety/anticipatory nausea	Benzodiazepine
Tumor-related elevated ICP	Glucocorticoid
Gastric stasis	Metoclopramide*
Stimulation of CTZ (drugs, uremia)	Dopamine or serotonin antagonist
Constipation	Laxative

**Indirectly causes acetylcholine release, which stimulates motility. This action is antagonized by drugs with anticholinergic properties such as promethazine or chlorpromazine.*

NOTES

SPECIFIC DRUGS

Dopamine Antagonists	
Prochlorperazine (Compazine)	po, IV, IM, 10 mg q 6 h; per rectum (PR), 25 mg suppository q 12 h
Chlorpromazine (Thorazine)	po, IV, IM, 25–50 mg q 6 h; PR, 25 mg suppository q 6 h (also anticholinergic)
Haloperidol (Haldol)	po, IV, subcutaneous (SQ), IM, 0.5–2 mg q 6 h
Thiethylperazine (Torecan)	po, IV, 10 mg q 8 h
Serotonin Antagonists	
Ondansetron (Zofran)	IV, 10 mg q 8 h; po, 4–8 mg q 8 h
Granisetron (Kytril)	IV, 10 µg/kg daily; po, 1 mg daily or bid
Dolasetron (Anzemet)	IV or po, 100 mg daily
NK1 Inhibitor	
Aprepitant (Emed)	125 mg day 1, 80 mg day 2–3 postchemotherapy; only approved indication is for highly emetogenic chemotherapy
Glucocorticoids	
Dexamethasone	po, IV, 2–10 mg q 6–12 h (dosing is empiric)
Benzodiazepines	
Lorazepam (Ativan)	po, IV, 0.5–2 mg q 6 h (helps prevent anticipatory nausea and vomiting)
Cannabinoids	
Dronabinol (Marinol)	po, 2.5–10 mg q 6 h (poorly tolerated in elderly people)
Antihistamines and Anticholinergics	
Promethazine (Phenergan)	po, IV, 25 mg q 6 h; PR, 12.5–50 mg suppository q 6 h; (antihistaminic, anticholinergic)
Diphenhydramine (Benadryl)	po, IV, 25–50 mg q 6 h (antihistaminic/anticholinergic)
Hydroxyzine (Vistaril)	po, IM, 25–50 mg q 6 h (antihistaminic/anticholinergic)
Scopolamine	patch, 1.5 mg during 3 days (anticholinergic)
Promotility	
Metoclopramide (Reglan)	standard oral dose of 10 mg ineffective against most nausea but useful for treating gastroparesis; high-dose IV, 1–3 mg/kg, effective against chemotherapy-induced nausea (weak antidopaminergic, 5HT ₃ antagonism; principal effect, stimulates acetylcholine release)
Drugs for Continuous Infusion	
Chlorpromazine	start at 1.0 mg/h IV, titrate up in 1-mg increments; typical response at 1–3 mg/h but can go higher; upper dose defined by unacceptable side effects
Metoclopramide	start at 1.0 mg/h IV or SQ

NOTES

Bibliography

Berger AM, Clark-Snow RA. Chemotherapy-related nausea and vomiting. In: *Principles and Practice of Palliative Care and Supportive Oncology*. Berger AM, Shuster JL Jr, von Roenn JH, eds. Philadelphia, PA: Lippincott-Raven; 2007:139–149.

Dalal S, Palat G, Bruera E. Chronic nausea and vomiting. In: *Principles and Practice of Palliative Care and Supportive Oncology*. Berger AM, Shuster JL Jr, von Roenn JH, eds. Philadelphia, PA: Lippincott-Raven; 2007:151–162.

Glare P, Pereira G, Kristjanson LJ, et al. Systematic review of the efficacy of anti-emetics in the treatment of nausea in patients with far-advanced cancer. *Support Care Cancer*. 2004;12(6):432–440.

Hallenbeck J. Non-pain symptom management. In: *Palliative Care Perspectives*. Oxford University Press; 2003. <http://www.mywhatever.com/cifwriter/library/70/4935.html>. Accessed July 27, 2009.

Nausea and Vomiting Resource. <http://www.nauseaandvomiting.co.uk/>. Accessed July 27, 2009.

Management of Nausea and Vomiting | Case Study | Faculty Guide

Objectives

1. Review the assessment of nausea and vomiting.
2. Develop a differential diagnosis for nausea and vomiting.
3. Develop a patient management plan for nausea and vomiting.

Teaching Points

- The care team knows more about the workup for suspected cancer than about the patients' chief complaint and subsequent symptom management.
- The complaint of “nausea” may represent one of many different sensations, symptoms, or syndromes, including GI reflux, anorexia, labyrinthine dysfunction, regurgitation, bowel obstruction, medication effects, anxiety (butterflies), and so forth. The assessment provided in the case is inadequate to determine exactly what the patient means by “nausea.” Only through a more detailed assessment can a differential diagnosis be established.
- The patient has constant nausea. If it is thought to be of gastrointestinal cause, around-the-clock antiemetics, at least for 24 hours, may be more appropriate than PRN orders. There should be better assessment and documentation of response after a PRN antiemetic is given to know if the prescribed medication is effective.
- Prochlorperazine (Compazine) is a reasonable starting drug for nausea in a case in which a dopamine antagonist may be helpful (see outline) or for nausea of unclear etiology. When this drug is not successful, reassessment is needed, and targeted drug therapy should be used whenever possible. Gastric compression and the associated dysmotility (squashed stomach syndrome due to an enlarged liver) are the possible cause of the

nausea. Early satiety with eating would be a strong hint in favor of dysmotility. Metoclopramide, a prokinetic, could be considered as an alternative drug in this case.

Case

Mrs. L. is admitted to your service late one evening because of four days of nausea and poor oral intake. She has a history of American Joint Committee on Cancer stage IIIA colon cancer at initial staging with no known interval metastases. Her physical examination is significant for mild pallor, dehydration, and a hard, enlarged, nodular liver. Abdominal radiographs showed a nonspecific gas pattern and an enlarged liver. Surgical evaluation in the emergency department before admission ruled out an acute surgical abdomen.

You think that Mrs. L. has metastatic colon cancer. IV fluids were begun, an abdominal computed tomography scan was ordered, along with a GI consultation for a liver biopsy and an oncology consultation to discuss potential chemotherapy options. On rounds the next morning, Mrs. L. says that she is still nauseated and that this feeling is constant. Admission orders include the following: prochlorperazine (Compazine), 10 mg po q 6 h, PRN, for nausea. Review of the nursing notes show that only one dose of prochlorperazine was given shortly after admission (12 hours ago) and that there has been no recorded vomiting.

QUESTIONS

1. Describe a differential diagnosis for nausea in this patient.
2. Is this an appropriate initial treatment plan? If not, describe the changes you would make.
3. If the nausea fails to respond to prochlorperazine, what would you do next?

NOTES



CHAPTER 7

Constipation



Learning Objectives

Attitudes

- Reflect on the management of constipation in surgical patients.
- Recognize that constipation is a common symptom that has a significant negative impact on quality of life in surgical patients with and without life-limiting disease.

Knowledge

- Describe at least five symptoms commonly associated with constipation.
- Describe at least two causes of constipation from each of the following categories: (1) mechanical obstruction, (2) drugs, (3) metabolic, (4) neurologic, and (5) miscellaneous.
- Know when to order diagnostic tests to help establish the cause of constipation.
- Understand the mechanism of action and common side effects of drugs from the following categories: (1) bulk laxatives, (2) large-bowel stimulants, (3) detergent laxatives, (4) osmotic laxatives, (5) lubricants, and (6) prokinetic drugs.
- Describe which drugs are not indicated for patients with poor mobility or poor oral intake.
- Understand when it is appropriate to begin prophylactic constipation treatment.

Skills

- Demonstrate communications skills necessary to take a thorough history from a patient with constipation.
- Construct a differential diagnosis for at least three patients with constipation.
- Demonstrate awareness of when to order abdominal radiographs.
- Develop an initial treatment plan for at least three patients with constipation.
- Demonstrate ability to choose and titrate an initial drug management plan.
- Demonstrate skill at treating constipation that is refractory to an initial treatment approach.
- Describe how to prescribe a prophylactic bowel regimen for a patient starting opioid analgesics.

NOTES

Pre/Post Test

- List three classes of drugs that cause constipation.
 - _____
 - _____
 - _____
- List one drug (generic and trade names) from each of the following laxative categories.
 - bowel stimulant: _____
 - detergent laxative: _____
 - osmotic laxative: _____
 - bulk laxative: _____
- List one laxative that is generally not recommended because of side effects.

- Bulk laxatives are *contraindicated* in patients who cannot increase their _____.
- A good prophylactic drug regimen for patients starting opioid analgesics would be (write drugs, doses, and schedule):

Answers

(1) iron, vinca alkaloids, anticholinergics, (2a) bisacodyl (Dulcolax), (2b) docusate (Colace, Surfak), (2c) magnesium citrate (Citromag™), lactulose (Cephulac, Chronulac), (2d) psyllium (Metamucil), (3) castor oil, (4) fluid intake, (5) senna, 2 tablets daily.

Definition

Acute: Less than six months; decrease in frequency or increase in difficulty initiating a bowel movement.

Chronic: Longer than six months; fewer than three bowel movements per week.

Bowel Function

Four interrelated factors contribute to bowel function:

(1) water content of stool, (2) gut motility, (3) solid stool content (such as fiber and bacteria), and (4) resistance (or lack thereof) to passage of stool.

1. **Water content**—About 8 to 9 L/d of fluid enters the gut; only 1 L/d reaches colon after small-bowel resorption. Daily stool content is about 200 mL/d; \pm 100 mL/d will lead to constipation or diarrhea. Slow gut transit results in more water being absorbed (constipation). Fast transit results in less water being absorbed (diarrhea). The presence of osmotically active particles in the gut results in water being retained in the stool (looser stools).
2. **Motility**—Gut motility is affected by extrinsic nerve stimulation and intrinsic systems speeding up or slowing down the gut. Greater motility is associated with looser stools (less water absorbed) and decreased motility with harder stools.
 - **Extrinsic system**
 - i. **Sympathetic outflow:** slows gut motility; T5–L2: inhibitory function via noradrenaline
 - ii. **Parasympathetic outflow:** speeds up gut motility; cranial distribution via vagus nerve (stomach-splenic flexure); sacral (S2–S4) (descending colon to anus): promotes peristalsis and gut fluid secretion
 - iii. **Supratentorial control, medial prefrontal and anterior cingulate gyrus:** timing and initiation of defecation

- **Intrinsic system**

Binding of certain gut receptors increases gut motility (acetylcholine, motilin), and others decrease motility (μ [opioid] receptors, dopamine). Nerve plexi in the wall of the gut respond to signals from these and other receptors. Mechanical stretch stimulates motility.

3. **Stool volume**—Increased stool volume results in increased motility (up to a point). When the diet is lacking in fiber, bulk fiber can alleviate constipation by increasing stool volume. However, excessive gut dilation impedes motility. Bulk laxatives, especially when taken with inadequate water or when there is a primary motility disorder, can result in large impactions.
4. **Resistance to stool passage**—Mechanical obstruction and pain with defecation (and resulting anal tightening) interfere with stool passage. Conversely, lubricants (mineral oil enemas) and detergent laxatives (docusate) may reduce resistance and ease stool passage.

Symptoms Commonly Associated with Constipation

- Increased passage of gas
- Abdominal pain; rectal pain
- Change in stool caliber
- Oozing of liquid or stool
- Anorexia; early satiety; nausea

NOTES

Differential Diagnosis

MECHANICAL OBSTRUCTION

- **Intraluminal:** colon cancer
- **Extraluminal:** malignant ascites, peritoneal carcinomatosis (ovarian, colon), adhesions, volvulus

DRUG-INDUCED

- **Opioids:** fentanyl and methadone may be less constipating than others
- Anticholinergics, tricyclic antidepressants, neuroleptics, antihistamines
- Chemotherapy, especially vinca drugs (vincristine, vinblastine)
- Serotonin-antagonist antiemetics
- Levodopa
- Calcium channel antagonists
- Iron, aluminum-containing antacids, barium
- Laxative abuse

METABOLIC

- Hypercalcemia; hypokalemia
- Diabetes (neuropathy); hypothyroidism; uremia

NEUROLOGIC

- Spinal cord injury: in high (quadriplegic), constipation common; in cauda equina injury, bowel atony with severe constipation and overflow incontinence due to parasympathetic denervation of sigmoid and/or rectum
- Paraneoplastic autonomic neuropathy (such as in small cell lung cancer, carcinoid tumors)
- Polymyositis

MISCELLANEOUS

- Dehydration, inactivity, bed rest
- Confusion, depression
- Pain on defecating: hemorrhoids, anal fissure, infection
- Generalized pain
- Irritable bowel syndrome

- Loss of normal bowel routine
- Inadequate privacy or positioning (use of bed pan)

Management

GENERAL MEASURES

- Prophylaxis whenever possible
- Reverse treatable causes
 - Rectal examination to exclude fecal impaction
 - Abdominal examination and/or radiographs may be needed to exclude bowel obstruction
- Restore daily bowel routine
- Increase fluids and activity as much as tolerated by clinical condition

DRUG THERAPY—DRUG CLASSIFICATION

Large-bowel stimulants (senna, bisacodyl, cascara, casanthranol, phenolphthalein)

- Directly increase bowel motility (require intact nerve plexi to work)
- Require transformation in liver (phenolphthalein, bisacodyl) or gut (senna, cascara)
- Abdominal cramps and increased gas common
- Senna, available as granules, pills, or liquids, commonly used for “natural” causes

Detergent laxatives (docusate, castor oil), also referred to as “wetting agents”

- Decrease surface tension, allow greater absorption of water/fat into dry stool
- Docusate a **weak laxative** (available as a sodium salt [Colace] or calcium salt [Surfak])
- Docusate should rarely be used as a sole agent for constipation. A recent systematic review suggests that docusate also has minimal added value when used in addition to other more potent laxatives.
- Docusate tastes bad (like concentrated soap). Liquid docusate should not be given by mouth. Pills may dissolve in patients’ mouths. (Patients with dementia have a high risk, and docusate should be avoided in this population.)

NOTES

- **NOTE:** *Castor oil is not recommended owing to expense, bad taste, and bowel stimulant effects.*

BULK LAXATIVES (psyllium, methylcellulose, polycarbophil, bran)

- Soluble and insoluble fiber supplements; inexpensive
- Require increased fluid intake for activity
- Abdominal cramps, increased gas, and allergic reactions can occur.
- Best use in ambulatory patients with reasonable gut motility without bowel obstruction who can take large volumes of liquid
- **NOTE:** *When used without increased fluid intake, constipation will worsen.*

OSMOTIC LAXATIVES (lactulose, sorbitol, glycerin, polyethylene glycol 3350 [GoLYTELY, MiraLAX], mannitol)

- Nonabsorbable sugars; work via osmotic effect in small and large bowel
- Lactulose, expensive, bad tasting, and increases abdominal gas; sorbitol, less expensive alternative; taste improved by mixing with apple juice
- Polyethylene glycol 3350, used as a bowel prep, can be given in smaller doses for constipation; MiraLAX (powder) has an advantage of being completely tasteless and can be added to any volume of fluids or food.

SALINE LAXATIVES (magnesium citrate or phosphate, sodium phosphate)

- Contain poorly absorbed salts and work osmotically; increase gastric, pancreatic, and small-bowel secretions
- Note: Do not use magnesium or phosphate products in patients with renal failure; do not use sodium products in patients with heart, liver, or kidney failure.
- Glycerin suppositories osmotically draw in water and lubricate hard stool.

PROKINETIC DRUGS

(bethanechol, neostigmine, metoclopramide)

- Decrease bowel transit time via increased motility. Of limited usefulness for colonic hypomotility due to toxic effects (bethanechol and neostigmine, cholinergic; metoclopramide, dopaminergic)

LUBRICANT (mineral oil)

- Can cause malabsorption, perianal irritation, and lipid pneumonia aspiration with oral intake. Enemas may be useful for hard stools encountering resistance in passage.
- **NOTE:** *Do not give orally or administer with docusate products.*

ENEMAS AND SUPPOSITORIES

- Bisacodyl suppository (10 mg), action in 15 to 60 minutes
- Glycerin suppository, action in 30 minutes
- Sodium phosphate enema (Fleet)
- Tap water, oil retention, soap suds enemas

OPIOID ANTAGONISTS (indirect prokinetics in opioid-induced constipation)

- Naloxone: variable results; may induce opioid withdrawal
- Others: methylnaltrexone, alvimopan; promising results in clinical trials

OTHER

- Octreotide has shown efficacy in managing constipation from the paraneoplastic autonomic neuropathy in small cell lung cancer.

“NATURAL” LAXATIVES

Many home recipes and/or natural food stores have products that contain a combination of raisins, prunes, applesauce, figs, and dates, with or without senna (also called Power Pudding).

Trade Names: All available *over the counter* except for lactulose and polyethylene glycol products

- Metamucil, Perdiem, Fiberall (psyllium)
- Citrucel (methylcellulose)
- Fiberall, Fibercon (calcium polycarbophil)
- MOM (magnesium phosphate)

NOTES

- Colace (docusate sodium); Surfak (docusate calcium)
- Senokot (senna); Senokot S (senna and docusate)
- Peri-Colace (docusate and casanthranol)
- Dulcolax (bisacodyl); Carter's (bisacodyl)
- Nature's Remedy (cascara)
- Ex-Lax, Feen-a-Mint (phenolphthalein); Correctol, Doxidan (phenolphthalein and docusate)
- Haley's M-O (mineral oil and magnesium hydroxide)
- Magnesium citrate (magnesium citrate)
- Chronulac, Cephulac (lactulose)
- Fleets Enema (sodium phosphate)

Drug Therapy— Management Plan

NOTE: *The following agents should generally be avoided: mineral oil, castor oil, and phenolphthalein.*

1. For prophylaxis (such as for a patient starting opioids) or for recent constipation start:
 - Psyllium product, *only* if patient able to increase fluid intake
 - Senna product or MOM; docusate can also be added
 - Increase dose of each product as needed (no upper dose limit except MOM in patients with renal failure); if no bowel movement at eight to 12 Senokot doses per day or 60 to 80 mL of MOM per day, go to Number 2.
2. For constipation refractory to Number 1, check for fecal impaction (see Number 4); start:
 - Bisacodyl (Dulcolax) PO 5 mg, up to 3 tablets TID
 - If no response, use one Dulcolax suppository.
3. For constipation refractory to Number 2, check for fecal impaction (see Number 4); start:
 - Magnesium citrate, eight oz, or
 - Lactulose, sorbitol, MiraLAX, or Fleet enema.
4. For patients with impaction:
 - Use sedatives and analgesics to relieve stress and pain of disimpaction.
 - Lubricate rectum; give glycerin suppository or oil-retention enema.
 - Manually disimpact rectum.
 - Give enemas to clear rectum.
 - Increase daily oral laxative program.

NOTES

Bibliography

- Hurdon V, Viola R, Schroeder C. How useful is docusate in patients at risk for constipation? A systematic review of the evidence. *J Pain Symptom Manage*. 2000;19:130–136.
- Klaschik E, Nauck F, Ostgathe C. Constipation: modern laxative therapy. *Support Care Cancer*. 2003;11(11):679–685.
- Levy MH. Constipation and diarrhea in cancer patients: part I. *Primary Care Cancer*. 1992:11-18.
- Levy MH. Constipation and diarrhea in cancer patients: part II. *Primary Care Cancer*. 1992:53-57.
- Mercandante S. Diarrhea, malabsorption and constipation. In: Berger A, Shuster J, Von Roenn J, eds. *Principles and Practice of Palliative Care and Supportive Oncology*. 3rd ed. Philadelphia, PA: Lippincott-Raven; 2007:163–175.
- Miles CL, Fellowes D, Goodman ML, et al. Laxatives for the management of constipation in palliative care patients. *Cochrane Database Syst Rev*. 2006(4):CD003448.
- Radbreuch L, Sabatowski R, Loick G, et al. Constipation and the use of laxatives: a comparison between transdermal fentanyl and oral morphine. *Palliat Med*. 2000;14:111–119.
- Sykes NP. The pathogenesis of constipation. *J Support Oncol*. 2006;4:213–218.

Management of Constipation | Case Study | Faculty Guide

Objectives

1. Describe the assessment of constipation.
2. Develop a differential diagnosis for constipation.
3. Develop a patient management plan for constipation.

Teaching Points

- The differential diagnosis in this patient is likely to include the following:
 - Opioid use
 - Inactivity
 - Spinal cord damage from compression fractures
 - Loss of normal bowel routine
 - Inadequate privacy or positioning (use of bed pan)
 - Pain
- Emphasize the importance of constipation as a source of patient suffering; understand the need for close attention to bowel habits, especially when opioids are used.
- Emphasize the need for frequent (daily) patient assessment of bowel function.
- Assessment should include a description of what the patient means by “constipation” and if there are other associated symptoms (such as straining, gas).
- Assessment should include an abdominal and a rectal examination, especially in this patient, to assess rectal tone and to rule out impaction.
- *Docusate* is a very weak laxative; it acts only as a mild detergent (wetting) agent.
- Regular use of a bowel stimulant (MOM or senna) is needed for patients taking opioids.
- Increasing fiber is not indicated unless patients can increase fluid intake.
- Review content outline for suggested treatment schema for this patient.

NOTES

CHAPTER 8

Malignant Bowel Obstruction



Learning Objectives

Attitudes

- Describe personal feelings about the role of surgery versus conservative management approaches in malignant bowel obstruction (MBO).
- Consider surgical and nonsurgical approaches to care management.
- Consider a treatment plan that includes interdisciplinary recommendations together with patient and family values.
- Consider socioeconomic, psychological, and spiritual dimensions in treatment planning.

Knowledge

- Describe the signs and symptoms of MBO.
- Explain the pathogenesis and epidemiology of MBO.
- Describe the natural history and prognosis of patients treated surgically compared with patients with inoperable MBO treated medically.
- Describe the differential diagnosis for MBO.
- Describe the indications and contraindications for laparotomy, gastrostomy tube placement, and endoscopic stenting.
- Know mortality and morbidity data for operative interventions for malignant obstruction.
- Explain the pharmacologic approach to and pharmacologic rationale for symptom management for patients with inoperable SBO.
- Explain the indications and contraindications for parenteral nutrition and artificial hydration for inoperable MBO.
- Develop a treatment plan that incorporates interdisciplinary involvement and patient and family values.

Skills

- Develop an initial and a long-term treatment plan for a patient with MBO.
- Use the skills of allied health care professionals in a collaborative effort to relieve symptomatic MBO.
- Demonstrate proficiency in therapeutic endoscopy, laparoscopy, bowel resection and anastomosis, formation of stoma, and management of common surgical complications.
- Prescribe opioids, antiemetics, antisecretory agents, and steroids appropriately for pharmacologic management of MBO.
- Demonstrate how to assist patients who have psychological or spiritual pain as a component of their MBO experience.
- Counsel a patient and family regarding symptom management.
- Counsel a patient and family about issues surrounding artificial hydration and nutrition.
- Counsel a patient and family about home care and hospice support for patients with inoperable MBO.

NOTES

Pre/Post Test

1. List three benign causes of bowel obstruction occurring in patients with known metastatic cancer.
 - a. _____
 - b. _____
 - c. _____
2. List three postoperative technical complications of laparotomy for MBO.
 - a. _____
 - b. _____
 - c. _____
3. List three classes of drugs useful in the nonoperative management of MBO.
 - a. _____
 - b. _____
 - c. _____
4. List two minimally invasive operative interventions for the relief of MBO.
 - a. _____
 - b. _____

Answers

- (1) adhesions, radiation stricture, internal hernia, (2) wound dehiscence, fistula, reobstruction, (3) opioids, antiemetics, and antisecretory agents, (4) intraluminal stent, PEG

Epidemiology and Pathogenesis

Cancer is the second most common cause of bowel obstruction. Bowel obstruction occurs in 5 percent to 43 percent of patients with a diagnosis of advanced primary or metastatic intraabdominal malignancy. The overall prognosis for this complication of cancer is poor. MBO has been noted to occur in 15 percent of terminally ill patients in a palliative care unit. Small bowel obstruction from malignancy is more common than colonic obstruction. Ovarian and colorectal cancers are the most common causes of malignant obstruction (5%–51% and 10%–28% of cases, respectively). Other tumors that lead to MBO with some frequency include metastatic breast, pancreatic, and lung cancer and melanoma. The mechanisms of obstruction from malignancy include intraluminal tumor growth from recurrent, metachronous, or metastatic disease; tumor blockage from extraluminal carcinomatosis or mass; intramural growth of tumor; and direct adherence and kinking from tumor. The effects of mechanical obstruction by tumor can be complicated by inflammatory edema, constipation, cancer or treatment-induced fibrosis, dysmotility, decreased production of intestinal enzymes and secretions, changes in fecal flora, and medication side effects. As a general rule, malignant obstruction of the small bowel is usually multifocal and due to carcinomatosis, while large bowel obstructions are more likely to be single site. The multiple pathophysiologic processes that collectively cause malignant intestinal obstruction offer opportunities for varied pharmacologic interventions as an alternative to invasive procedures.

Symptoms and Signs

The symptom complex of abdominal pain, nausea, constipation, and vomiting in a patient with a known cancer diagnosis is highly suggestive of MBO. Abdominal distention is more pronounced with distal obstruction, although abdominal distention may be minimal with proximal obstruction or when bowel is nondistensible due to tumor encasement. Typically, pain due to bowel obstruction is intermittent or colicky, although this symptom complex can be obscured by ongoing cancer pain or other syndromes not related to bowel obstruction. Pain from small bowel obstruction tends to be periumbilical. In partial obstruction, loose stools will be passed unless the obstruction becomes complete. The finding of ascites, cachexia, or multiple palpable masses, alone or in combination, in addition to obstructive symptoms is particularly suggestive of inoperable malignant obstruction. Differential considerations include constipation, adhesions, internal hernias, volvulus, radiation-induced stricture, drugs, metabolic derangements, and neurogenic reasons for gut dysmotility.

NOTES

Management

INITIAL STEPS

1. Fluid and electrolytes
2. Nasogastric (NG) decompression: some obstructions will resolve with decompression alone
3. Diagnostic studies
 - Abdominal radiographs
 - Computed tomography (CT) to determine presence and level of obstruction and assess extent of cancer

INTERVENTIONS FOR CONTINUED OBSTRUCTION

1. Operative interventions
 - Laparotomy for tumor debulking and/or bowel resection with reanastomosis or ostomy
 - Bypass procedures (preferred for radiation-induced obstruction)
 - Resection or bypass can be accompanied by gastrostomy placement; or, gastrostomy alone may be performed at laparotomy if disease too extensive.
 - A laparoscopic approach is viable when the operator's experience and judgment permit. Carcinomatosis and dense radiation-induced adhesions may limit this option.
2. Endoscopic interventions
 - Expandable stent insertion for single-site obstructions of upper gastrointestinal (GI) tract and distal colon
 - Percutaneous endoscopic gastrostomy (PEG) placement—appropriate for patients who are not candidates for an operative intervention or who do not respond to medical management
3. Interventional radiology techniques
 - PEG placement (see aforementioned indications)
 - Cecostomy—a minimally invasive option for closed loop distal colonic obstruction

4. Medical management

For patients unable to benefit from an operative or interventional approach, medical management through pharmacotherapy can be quite effective to limit pain, nausea, and bowel secretions sufficient to eliminate the need for (NG) suctioning and IV hydration. In some cases, a regular diet can be resumed if an occasional emesis (once a day) is tolerable. During titration of medications, IV fluids should be restricted to 50 mL/h. When the NG output is less than 100 mL/d, the NG tube can be discontinued or clamped on a trial basis and then removed if tolerated.

Symptom	Drug	Starting Dose
Continuous abdominal pain	Opioids Parenteral nonsteroidal antiinflammatory agent (ketorolac)	
Crampy abdominal pain	Glycopyrrolate (or another antisecretory, anticholinergic medication)	0.2–0.4 mg q4 h PRN
Nausea without cramps in partial MBO	Metoclopramide (Do not give with anticholinergics or in complete obstruction.)	30–60 mg subcutaneously (SQ)/IV during 24 h; 10 mg SQ/IV q 6 h PRN, up to 120 mg/24 h (total)
Nausea and vomiting	Haloperidol	5 mg IV or SQ during 24 h 1 mg IV or SQ q 6 h PRN
	Dexamethasone (central nervous system-acting antiemetic and reduces inflammatory component of obstruction)	4–8 mg IV once a day, up to 5 days
Copious emeses refractory to opioid, anticholinergic, and antiemetic regimen	Octreotide (add to previous regimen)	100–600 µg SQ during 24 h intermittently or as infusion

NOTES

DECISION-MAKING

Selection of treatment for MBO is notoriously difficult, even for the most experienced surgeons, because of the technical, emotional, and psychological difficulties for all involved. The greatest psychological trap for the surgeon is the need to “do something” to escape the sense of helplessness in this clinical scenario, even if doing so is unlikely to benefit the patient. The penalty for operative management of MBO is frequently severe: 5 percent to 32 percent mortality, 42 percent morbidity, and a reobstruction rate of 10 percent to 50 percent. Complications of surgery include those associated with any major operative intervention and anesthesia, in addition to procedure-specific complications such as wound or anastomotic dehiscence, fistula, hernia, and stoma problems. Most data about outcomes are of limited usefulness owing to the retrospective nature, the heterogeneity of the symptom complex, and the traditional focus of reviews on mortality and morbidity instead of quality-of-life outcomes. However, a completely nihilistic attitude toward surgery is unwarranted because 3 percent to 48 percent of obstructions occurring in patients with previously diagnosed malignancy are due to benign causes. However, surgery is less likely to benefit patients with poor performance status, multiple sites of obstruction, carcinomatosis, ascites, and multiple palpable masses.

Accurate prognostication and empathic communication lay the groundwork for therapeutic decisions. Clear communication about the limitations of surgery is an essential part of the consent process: *Restoration of bowel patency will not reverse weight loss and anorexia caused by concurrent widespread metastatic disease.* Consultation with other care providers, especially medical oncologists, palliative care clinicians, and gastroenterologists, radiologists, dieticians, and enterostomal therapists, is vital in developing a comprehensive treatment plan.

MEDICAL MANAGEMENT: ARTIFICIAL NUTRITION AND HYDRATION

When patency of the GI tract is not possible, patients can achieve good symptom relief using the pharmacologic approach outlined in the preceding text. However, except in rare cases, patients with a complete obstruction will not be able to sustain themselves with oral fluid/food intake, raising the issue of appropriateness of artificial hydration/total parenteral nutrition (TPN). Decision making should be guided by helping patients identify concrete goals that continued artificial hydration/nutrition can help meet (eg, attend an upcoming family event). If artificial hydration/TPN is used, it should be modified to reduce the formation of ascites, pleural effusions, pulmonary edema, and increased airway and gut secretions. In cases in which the patient has no goals and there is an overwhelming cancer burden, there is no role for continued artificial nutrition and hydration, and it can be discontinued, shifting the focus of care to symptom relief for the remaining days or weeks of life. All patients with inoperable MBO are candidates for hospice care; most hospice agencies can manage complex symptom-control regimens in the home.

NOTES

Bibliography

- Bicanovsky LK, Lagman RL, Davis MP, et al. Managing nonmalignant chronic abdominal pain and malignant bowel obstruction. *Gastroenterol Clin North Am.* 2006;35(1):131–142.
- Krouse RS. Surgical management of malignant bowel obstruction. *Surg Oncol Clin N Am.* 2004;13(3):479–490.
- Krouse RS, McCahill LE, Easson AM, et al. When the sun can set on an unoperated bowel obstruction: management of malignant bowel obstruction. *J Am Coll Surg.* 2002;195(1):117–128.
- Mount BM. Bowel obstruction. In: MacDonald N, ed. *Palliative Medicine. A Case-Based Manual.* Toronto, Canada: Oxford University Press; 1998:34–47.
- von Gunten C, Muir JC. Fast Fact and Concept #045: Medical Management of Bowel Obstruction. 2nd ed. August 2005. End-of-Life/Palliative Education Resource Center Available at: http://www.eperc.mcw.edu/fastFact/ff_45.htm. Accessed July 23, 2009.

Case Study | Faculty Guide

Objectives

1. Describe the assessment of suspected MBO.
2. Develop a differential diagnosis for the symptom complex of abdominal pain, nausea, and vomiting.
3. Develop a treatment algorithm for MBO.

Teaching Points

- Bowel obstruction is a common complication of advanced intraabdominal and pelvic malignancy.
- Emphasize the high morbidity, mortality, and rate of recurrent obstruction associated with surgical management of bowel obstruction due to advanced malignancy.
- Autopsy studies have shown that gangrene rarely occurs in malignant obstruction. This finding allows time for due deliberation in management decisions and also is the rationale for the safety of nonoperative management.
- Computed tomography imaging is the diagnostic modality of choice.
- Nasogastric suctioning is not a destination therapy for MBO. It is a temporary measure for immediate relief of symptoms, preoperative preparation, and, not infrequently, it will encourage spontaneous resolution of the obstruction.
- Selection of therapy should consider the following: (1) the natural course and prognosis of the disease, (2) the relevance of the treatment to patient-identified goals and passions, and (3) the experience and strengths of the management team. The positive value of a medical treatment is not intrinsic, but defined only in context with its application and outcome.
- Treatment of MBO requires an interdisciplinary approach. Physical illness is frequently a useful metaphor for the nonphysical domains of the patient's experience. The obstructed state makes it difficult for mental digestion, too!
- Surgery is more likely to help in patients with a better prognosis, good performance status and nutrition, and a single site of obstruction.
- Surgery is less likely to help in patients with poor performance status, ascites, multiple palpable masses, and carcinomatosis.
- Surgery and medical management are equally effective at controlling symptoms until death.
- The diagnosis of inoperable MBO should prompt discussion about prognosis, resuscitation status (DNR), nutrition and hydration, and referral to hospice services.
- Families of patients who have selected medical management should be counseled about the physiology of nausea and vomiting to better understand the rationale and limitations of medical therapy. Patients will tolerate an occasional emesis as long as nausea is controlled.
- The decision to initiate TPN should be based on measurable objectives, i.e., increased lean muscle mass, improved performance status in the context of a timed trial.
- The goal of pharmacotherapy for MBO is to decrease pain, nausea, and bowel secretions enough to eliminate the need for NG suctioning and IV hydration.
- Supplemental hydration is indicated only for patients who become dehydrated despite oral intake and if hydration for the purpose of extending life is consistent with the patient's goals.
- Although an operation may save a life, it can also save hope if symptoms are effectively controlled. The surgeon's demonstrated commitment to the ongoing care of the patient with MBO is as important to the patient and family as any operative intervention that may have been done or left undone.

NOTES

Case

Mrs. J., a 54-year-old mother of three, is admitted to the emergency department with a several-day history of abdominal pain and distention, nausea, and intermittent vomiting. She has no appetite and has not had a bowel movement in several days. Two years previously, she underwent a sigmoid colectomy for a stage III carcinoma of the colon. She subsequently received FOLFOX4 chemotherapy. Her medications include atenolol, 25 mg daily, and sertraline, 25 mg daily. The last CT evaluation showed no evidence of recurrence, although the CEA level was slightly elevated from a previous level of 2. Examination reveals that she appears well nourished and afebrile. The abdomen is distended, tympanitic, and mildly tender to palpation. Occasional high-pitched bowel sounds are heard. Her previous incision is well healed with no evidence of incisional hernia. The rectum is empty. The hematocrit is 34 percent. A plain abdominal film shows a markedly dilated colon and dilated loops of small bowel. No free air is seen.

QUESTIONS

1. Describe initial appropriate management of this patient.
2. Develop a ranked-order differential diagnosis.
3. How would you next proceed in your evaluation?

Case

Mrs. J. undergoes CT of the abdomen. It reveals dilatation of the small bowel and colon to the level of the rectosigmoid junction with an abrupt cutoff. An indistinct mass and induration surrounding the point of obstruction are seen. Several hypodense lesions are seen in the right lobe of the liver. There is no free air or ascites.

QUESTIONS

1. Describe how you would convey this information to Mrs. J.
2. What other information would be relevant before selecting treatment?
3. What treatment would you recommend and why?

Case

Mrs. J. elected to undergo an attempt at endoscopic stenting through the obstructed site. At endoscopy, the mucosa just distal to the obstruction is friable and studded with white nodules. The scope cannot pass through the obstruction.

QUESTIONS

1. Describe how would you convey this information to Mrs. J.
2. What treatment options are now available to Mrs. J.?

Case

Mrs. J. underwent an exploratory laparotomy, segmental colon resection, and formation of an end-sigmoid colostomy. At laparotomy, residual tumor was noted in the left colic gutter. Multiple liver metastases were palpated in the right lobe of the liver. Several small implants were noted in the small bowel mesentery. Her postoperative course is uneventful, and she is discharged.

QUESTIONS

1. Do you agree with the operative management? If not, what would you have done differently?
2. What would your recommendations for follow-up care be at discharge?

Case

Mrs. J. subsequently underwent a salvage regimen of chemotherapy. Five months following the laparotomy, she returns to the emergency department with a several-day history of abdominal pain and distention with frequent green emeses. In the exam, she appears cachectic, pale, and apprehensive. Her abdomen is moderately distended. Several masses are palpable. High-pitched bowel sounds are heard. Several liters of bilious drainage are suctioned following placement of an NG tube. A plain film shows multiple air fluid levels consistent with small bowel obstruction. When you tell her about the radiographic findings, she asks you, “Am I dying?”

NOTES

QUESTIONS

1. How do you respond to her question?
2. What treatment options are available?

Case

Mrs. J. selects medical management for her MBO. She indicates her strong wish to return home.

QUESTIONS

1. Outline an algorithm for medical management.
2. How do you prepare her for home discharge?

NOTES



CHAPTER 9

Cachexia, Anorexia, Asthenia, and Fatigue (Wasting Syndromes)



Learning Objectives

Attitudes

- A greater appreciation for the multifactorial nature of wasting syndromes in terms of pathophysiology *and* treatment.
- Understand that cachexia and loss of lean body mass cannot always be “overpowered” by additional nutritional supplementation.
- Asthenia, anorexia, and fatigue significantly affect quality of life for patients and have a major effect on health outcomes and therapeutic options, including surgery.

Knowledge

- Describe the relationship between appetite and the usefulness of nutritional support.
- Describe common factors contributing to wasting syndromes.
- Describe common benefits and burdens of appetite and psychostimulants in treating anorexia and fatigue.

Skills

- Make a list of factors likely to contribute to wasting syndromes, with attention to how correctible these factors might be.
- Develop an individualized care plan for patients with a wasting syndrome.
- Use artificial nutrition in cases likely to benefit from such therapy, and avoid use in cases with little chance of benefit.

NOTES

Pre/Post Test

1. Name three common but reversible (treatable) causes of wasting syndromes:

- a. _____
- b. _____
- c. _____

2. Name two common causes of cachexia that are usually not reversible:

- a. _____
- b. _____

3. Name a commonly used appetite stimulant:

4. Use of total parenteral nutrition (TPN):

List criteria you might use in deciding to use TPN in the care of a patient with cachexia or significant loss of lean body mass:

List exclusion criteria or relative contraindications to TPN.

Answers

(1) sepsis, adrenal insufficiency, anemia, (2) cancer, chronic obstructive pulmonary disease, (3) steroids, (4) reversible cause of cachexia, lack of gut function, end-stage, irreversible disease, presence of gut function.

Definitions

Cachexia: Body wasting

Anorexia: Lack of appetite

Asthenia: Weakness

Fatigue: A subjective sensation of weakness or lack of energy; may also refer to a decrement in performance of physical or mental tasks

Differential Diagnosis

Cachexia, anorexia, asthenia, and fatigue often overlap, commonly with loss of lean body mass and subjective weakness and lack of appetite. Differential diagnosis should first focus on identifying correctable (or “improvable”) causes of the aforementioned conditions, when present, and in helping clinicians tailor supportive measures.

Common Causes

- Endocrine abnormalities (hypothyroidism, adrenal insufficiency)
- Depression
- Anemia
- Substance abuse, neglect, abuse
- Neurologic and muscular disorders (dementia, stroke, multiple sclerosis, myopathies, postpolio syndrome, etc.)
- Sleep disorders (sleep apnea)
- Congestive heart failure
- Chronic obstructive pulmonary disease
- Cancer
- Inflammatory states, whether infectious or autoimmune
- Medication side effects

Great variability exists in the degree to which a primary disease process giving rise to these symptoms can be cured or ameliorated. Even within a general category of illness, such as cancer, many factors may contribute to the problem. Cancer and cancer therapy may directly interfere with the ability to take in adequate nutrition, for example, in

patients with head and neck cancer undergoing surgical resection and radiation therapy. Cancer or cancer therapies, radiation therapy, chemotherapy, and surgery can give rise to chronic inflammatory states that increase catabolism of lean body mass, decrease the ability of the body to use available nutrition, and decrease appetite for food.

Key point in evaluating patients with cachexia—Appetite (or lack thereof) serves as a very good indicator of the body’s ability to use nutrition, if available, in building lean body mass and increasing energy. Hungry patients will usually benefit from nutritional supplementation or artificial nutrition, enteral or parenteral, if unable to eat on their own. Conversely, *lack of appetite in the absence of nausea* suggests that the body may have trouble utilizing nutrients, even if provided. In many cases, lack of appetite and cachexia are the result of a cytokine-mediated inflammatory state. Advanced cancer, chemotherapy and radiation therapy, chronic infections (for example, osteomyelitis), and surgery all can give rise to such inflammatory states and loss of lean body mass. In such cases, addressing underlying causes of inflammation, when possible, is critical if efforts toward increasing lean body mass are to be successful. Simply trying to “overpower” the system through artificial nutrition will not usually work, as cellular uptake and intracellular utilization of nutrients in protein synthesis are impaired in cytokine-mediated inflammatory states. Therapies targeting these inflammatory states directly (rather than the underlying disease process) are being developed but are not commonly available at present.

NOTES

Treatment

In many cases, the cause of the disorder is multifactorial. Rather than attempting to find *the* cause, clinicians are advised to consider variables that may contribute to the syndrome. For example, patients with a chronic medical condition, such as cancer or multiple sclerosis, may also be depressed, have an altered sense of taste, have a sleep disorder, have poor nutrition due to inability to shop or cook, be deconditioned due to lack of exercise, and be having side effects of medications. Optimal management considers such factors in the development of a treatment plan. It is impossible to discuss all possible therapies here. Two broad categories of therapy for anorexia and asthenia/fatigue are outlined briefly.

Appetite Stimulants

Rule of thumb: Appetite stimulants, if they work, do just that—they stimulate appetite. As a general rule they do *not* build lean body mass, strength, or endurance. Weight gain associated with stimulants is usually water or fat, not protein.

Rule of thumb: If stimulants are helpful (and appetite increases), continue to use them. However, medications should generally be discontinued if *not* effective or if they stop working, as often happens.

- **Megestrol (Megace):** Generally well tolerated; weight gain is water or fat, not lean body mass; high doses (circa 800 mg/d) usually necessary for effect
- **Cannabinoids (for example, dronabinol):** May be similarly effective; central nervous system effects may be euphoric or dysphoric; greater risk of dysphoria/delirium in elderly patients)
- **Steroids:** Similarly effective for appetites; other effects desirable (euphoria, relief of pain due to tumor compression, antiinflammatory effect) or undesirable (delirium, glucose intolerance, steroid myopathy, bone loss)

Energy Stimulants/ Psychostimulants

As a class, these agents may reduce fatigue and improve appetite and help with depression. Negative side effects may include jitteriness, agitation/anxiety, insomnia, and, when used in high doses or in people at high risk for cardiac complications, adverse cardiac effects. While appetite may be increased, there may be little, if any increase in lean body mass or weight associated with their use, as increased activity may burn any excess calories.

Commonly used agents

- Caffeine
- Dextroamphetamine
- Methylphenidate
- Pemoline
- Modafinil

NOTES

Bibliography

Armes J, Krishansamy M, Higginson I, eds. *Fatigue in Cancer*. New York, NY: Oxford University Press; 2004.

Bruera E, Beattie-Palmer LN. Pharmacologic management of nonpain symptoms in surgical patients. *Surg Oncol Clin N Am*. 2001;10(1):89–107.

Del Fabbro E, Dalal S, Bruera E. Symptom control in palliative care, part II: cachexia/anorexia and fatigue. *J Palliat Med*. 2006;9(2):409–421.

Dunlop RJ, Campbell CW. Cytokines and advanced cancer. *J Pain Symptom Manage*. 2000;20(3):214–232.

Fearon KC, Barber MD, Moses AG. The cancer cachexia syndrome. *Surg Oncol Clin N Am*. 2001;10(1):109–126.

Hallenbeck J. Fast Fact and Concept #010: Tube Feed or Not Tube Feed. 2nd ed. End-of-Life Physician Education Resource Center. Available at: http://www.eperc.mcw.edu/fastFact/ff_010.htm. Accessed July 23, 2009.

Hallenbeck J. Non-pain symptom management. In: *Palliative Care Perspectives*. New York, NY: Oxford University Press; 2003:75–116.

House R, Descotes J, eds. *Cytokines in Human Health*. Totowa, NJ: Humana Press; 2007.

Mirhosseini N, Fainsinger RL, Baracos V. Parenteral nutrition in advanced cancer: Indications and clinical practice guidelines. *J Palliat Med*. 2005;8(5):914–918.

Case Studies for Small Group Discussion

Case 1

A 58-year-old man underwent resection of a head and neck carcinoma, followed by radiation and chemotherapy. When seen in the ENT clinic postoperatively, he complains of severe sore throat, difficulty swallowing, dry mouth, and altered taste. He is taking morphine for pain and mentions that he is constipated. He is losing weight, although he says his appetite is fair. He complains of being tired all the time and admits to being depressed.

Case 2

A 62-year-old woman with advanced pancreatic cancer is admitted to the surgery service with proximal small bowel obstruction, thought to be secondary to the cancer. She is cachectic and bedridden, but alert. She tells you that during the past several months she has had very little appetite. Laboratory examination reveals an albumin level of 1.3 g/dL. Given this, the team believes she is a poor operative risk. TPN is discussed as a possible means of improving her status in hopes that she might be able to undergo surgery.

QUESTIONS

1. List for each case possible factors that might be contributing to the patient's anorexia, asthenia, and fatigue.
2. Categorize possible factors as to whether they can be corrected or improved on.
3. Based on these lists, sketch out a care plan for each patient.
4. In discussing your care plans, you will likely encounter some questions to which you do not know the answer. (Example: What therapeutic options for xerostomia [dry mouth] exist in patients after head and neck surgery?) Jot these down and discuss how you might pursue them. How much of this care would you as a surgeon be willing to initiate, and where might you want help from someone like a palliative care consultant?
5. Artificial nutrition is an option that might be considered for patients in both cases. Contrast the patients in terms of the likelihood that each might benefit from artificial nutrition.



CHAPTER 10

Artificial Hydration and Nutrition



Learning Objectives

Attitudes

- Reflect on personal values regarding the use of artificial nutrition and hydration (ANH).
- Understand the cultural and spiritual implications for patients and families associated with ANH.
- Understand the ethical, professional, and legal considerations that accompany a decision to withdraw or withhold ANH.
- Recognize that quality of life during the dying process may be improved by not providing ANH.

Knowledge

- Describe the benefits and burdens of ANH.
- Describe the different forms of ANH and their application to different disease states.
- Describe the pertinent ethical and legal questions associated with use of ANH.
- List important questions to ask when a patient or patient's family requests placement of a feeding tube for ANH.

Skills

- Demonstrate cultural and spiritual sensitivity toward patients using or considering ANH.
- Develop a plan for assessing and counseling patients and families who request placement of a surgical feeding tube for ANH.
- Demonstrate competence recommending alternatives to ANH for patients with severe, life-limiting disease.

NOTES

Pre/Post Test

1. Name three types of artificial nutrition.

- a. _____
- b. _____
- c. _____

2. Name three conditions in which ANH has proven benefit in terms of prolonged survival.

- a. _____
- b. _____
- c. _____

3. Name three risks or burdens of ANH.

- a. _____
- b. _____
- c. _____

Answers

(1) nasogastric (NG) tube, jejunostomy (J) tube; total parenteral nutrition (TPN), (2) persistent vegetative state, amyotrophic lateral sclerosis, early head and neck cancer, (3) increased risk of secretions and aspiration, gastrostomy (G) tube complications (infection, bleeding), need to use restraints

Definition

The provision of food and drink to loved ones is an important concern for families of dying patients. When patients cannot safely eat or drink by mouth, families may often request that nutrition and hydration be administered by artificial means. As with all treatment decisions, the decision to administer ANH should be informed by the patient's own wishes and the current data regarding the relative benefits and burdens of the intervention in question.

Artificial nutrition: includes any form of nonoral feeding, including orogastric or NG tube, percutaneous G tube (PEG), J or gastrojejunostomy (G-J) tube, or TPN.

Artificial hydration: provision of water or electrolyte solutions by nonoral route; includes intravenous (IV), hypodermoclysis, and NG, G, and G-J tubes.

Relative Benefits and Burdens of Artificial Nutrition and Hydration

Evidence varies regarding the benefits and burdens of ANH depending on the patient's underlying disease. In general, ANH provides the greatest benefit for patients receiving short-term critical care for reversible illness (such as sepsis) and the least benefit for patients with progressive terminal illness (such as advanced dementia or cancer).

Benefits

Survival: ANH can prolong life across a population of patients in the setting of permanent vegetative state, amyotrophic lateral sclerosis, early head and neck cancer, short-gut syndrome, acute stroke, selected HIV cases, and proximal bowel obstructions due to cancer. Although ANH may prolong survival in an individual patient, when a large population of patients with advanced dementia or advanced cancer is studied, ANH seems not to impact survival. Advanced dementia and cancer are chronic, systemic, terminal illness for which long-term provision of ANH seems to have little impact in terms of lengthening survival.

Quality of life: ANH may improve quality of life by abating hunger and thirst and improving energy in selected patients (such as early head and neck cancer). In patients who are near death, hunger and thirst are naturally suppressed and, therefore, not affected by ANH.

Psychological benefit for caregivers: Providing ANH allows family members and caregivers to hold out hope for recovery and avoid guilt about withholding nutrition.

Burdens

Aspiration: In patients with dementia, aspiration risk is the same or greater than with oral feeding. In the last days of life, ANH may increase oral and pulmonary secretions, thereby increasing distress.

Tube complications: ANH (especially through NG and G tubes) can increase discomfort and agitation. G-tube placement is associated with near- and long-term surgical complications (such as bowel perforation, leak, abscess).

Quality of life: ANH may worsen quality of life by denying the pleasure of eating or reducing contact with caregivers. ANH increases the likelihood that patients will need restraints, which, in turn, increases distress and pressure ulceration.

NOTES

Legal and Ethical Considerations

There is widespread, unanimous agreement that withdrawing and withholding a medical treatment are ethically identical. The law treats ANH as a medical treatment that can be withheld or withdrawn, especially if the patient's wishes are clearly known (the patient has decision-making ability or the patient's wishes were clearly expressed in an advance directive). If the patient's wishes are not known, different states have different requirements about the level of supporting evidence that surrogate decision-makers are required to furnish to withhold or withdraw ANH. Consultation with social work, legal affairs, or ethics personnel may be appropriate.

Cultural and Spiritual Considerations

The provision of food and drink to the sick is an important cultural symbol and has significant spiritual implications for caregivers. The notion of withholding food and drink from loved ones can be distressing for families and a source of significant guilt and spiritual angst. Most religions recognize the importance and spiritual benefit of hand-feeding sick people who are able to eat but do not mandate the provision of ANH. However, within all faiths, there is a spectrum of beliefs and devotions. When the decision to provide or forgo ANH is accompanied by significant spiritual distress, consultation with chaplaincy and the patient's or family's spiritual leader is advisable.

Physicians need to be aware of their own deeply held religious or cultural beliefs about ANH. These beliefs should not impede impartial recommendations based on current medical evidence.

NOTES

The Surgeon's Role in Counseling Patients and Families

Surgeons are often asked to place tubes that will be used to administer ANH. Surgeons can, therefore, have an important role in assisting patients and families making this difficult decision. Several questions should be addressed:

1. Does the patient have decision-making capacity? If not, who is the patient's surrogate decision-maker (such as power of attorney for health care, legal guardian)? What information is the surrogate using to guide the decision—an advance directive or previously expressed wishes? Have the surrogates asked themselves: "What would _____(the patient) want?"
2. Is the patient dying, for example, advanced dementia or advanced cancer? This question may never have been raised in previous discussion with family or even in the minds of the surgeon and referring physician. Once dying is openly acknowledged, many patients and families will unequivocally forgo ANH. To avert an act of "surgical hubris," surgeons must balance their deeply rooted impulse to help against the ethical principles of nonmaleficence and beneficence.
3. What are the goals of care motivating the decision for ANH? Is ANH in this particular clinical scenario likely to prolong life? Decrease suffering? Remind family members that food and fluids can always be given by hand as tolerated and that aggressive comfort measures such as pain and symptom control will always be administered. Goal clarification is a much more helpful starting point than referring to the existing evidence base when deciding to engage ANH or TPN as an adjunct to management of inoperable malignant bowel obstruction.
4. Are the patient and surrogates basing their decision on particular cultural or religious beliefs? Have they consulted with a spiritual leader? Offer to arrange a visit from a chaplain if desired.
5. If the current evidence suggests that ANH would not achieve the goals of the patient in this particular setting, it is appropriate to make a recommendation against placing a G tube or commencing ANH. Families may be looking for permission to *not* administer ANH.
6. If the decision has been made to commence ANH, establish a time frame after which the intervention will be reevaluated (for example, 1–2 months) to see if it is still achieving the goals of care (such as improved nutritional status, decreased suffering). If not, the ANH can be withdrawn after further discussion with the patient's surrogates.

Bibliography

- Casarett D, Kapo J, Caplan A. Appropriate use of artificial nutrition and hydration: fundamental principles and recommendations. *N Engl J Med*. 2005;353:2607–2612.
- Finucane TE, Christmas D, Travis K. Tube feeding in patients with advanced dementia. *JAMA*. 1999;282:1365–1370.
- Hallenbeck J. Fast Fact and Concept #010: Tube feed or not tube feed? 2nd ed. August 2005. Available at: http://www.eperc.mcw.edu/fastFact/ff_010.htm. Accessed July 29, 2009.
- Hofmann B, Håheim, Sørdeide JA. Ethics of palliative surgery in patients with cancer. *Br J Surg*. 2005;92:802–809.
- Rabeneck L, McCullough LB, Wray NP. Ethically justified, clinically comprehensive guidelines for percutaneous endoscopic gastrostomy tube placement. *Lancet*. 1997; 349:496–498.
- Weissman D. Fast Fact and Concept #084: Swallow studies, tube feeding and the death spiral. 2nd ed. January 2008. Available at: http://www.eperc.mcw.edu/fastFact/ff_084.htm. Accessed July 29, 2009.

NOTES

Learning Activity | Case Study and Role Play

Objectives

1. Reflect on the surgeon's role and responsibilities for counseling patients about ANH.
2. Develop a system for assessing patients who are considering ANH.
3. Be able to discuss the benefits and burdens of ANH in different disease states.
4. Understand the surgeon's own biases regarding ANH and how these can affect patient interactions.

Case

Mr. A. is a 75-year-old patient with worsening dementia who has been admitted from a long-term care facility for treatment of pneumonia. He has been experiencing progressive decline during the last few months, with several admission for infections. The staff at the care facility report that Mr. A. is showing decreasing interest in food. His oral intake has declined dramatically in recent weeks.

The medical team has discussed placement of a G tube for the provision of artificial nutrition and hydration. Mr. A.'s wife replies that, "Of course he should have a feeding tube placed. We don't want him to starve to death." You are called by the medical team to assess the patient and arrange placement of a G tube.

QUESTIONS

1. What is the medically relevant information to obtain when you assess this patient for a G tube?
2. What are the important ethical and cultural considerations about assessing this patient for a G tube?
3. What are your own opinions about ANH in a patient such as Mr. A.? How do you manage those opinions and biases when evaluating patients for a G tube procedure?

Role Play

Have the instructor play the part of the patient's wife. Mrs. A. is concerned for her husband's welfare and comfort. She does not want him to suffer. She is dedicated to providing any treatments that will give him the longest survival with the best quality of life, which she believes include ANH.

Have a trainee volunteer play the part of the consultant surgeon. After introducing himself or herself to Mrs. A., instruct the trainee to explore with Mrs. A. the different motivations and concerns she has about ANH for her husband. Instruct the student to demonstrate how he or she would counsel Mrs. A. about the relative benefits and burdens of ANH for Mr. A. and any alternative treatments or strategies that might be used.

NOTES

CHAPTER 11

Selected Symptoms

“Symptoms, then, are in reality nothing but the cry from suffering organs.”

—Jean Martin Charcot, MD

Learning Objectives

Attitudes

- Reflect on previous experiences with patients who experience pruritus, hiccups, or insomnia.
- Recognize that pruritus, hiccups, and insomnia can be debilitating symptoms with significant effects on quality of life for patients who are dying or have severe, life-limiting diseases.
- Recognize that as a caregiver, inquiring about and addressing selected symptoms besides pain and dyspnea in dying patients can significantly reduce suffering.

Knowledge

- Develop an organized approach to the assessment of symptoms of pruritus, hiccups, and insomnia.
- Develop a differential diagnosis for pruritus, hiccups, and insomnia with emphasis on the causes relevant to surgical patients with severe, life-limiting illness.
- Differentiate between first-line therapies and alternative agents that can be used in persistent or refractory cases of pruritus, hiccups, and insomnia.

Skills

- Demonstrate communication skills interviewing and assessing patients who complain of pruritus, hiccups, and insomnia.
- Develop a care plan using first- and second-line agents for the treatment of pruritus, hiccups, and insomnia.
- Demonstrate the ability to counsel patients about nonpharmacologic remedies for pruritus, hiccups, and insomnia.

NOTES

Pre/Post Test

1. List three causes of pruritus not related to primary skin disorders.
 - a. _____
 - b. _____
 - c. _____
2. List two pharmacologic treatments for pruritus that are not antihistamines.
 - a. _____
 - b. _____
3. List three structural causes of hiccups pertinent to surgical patients.
 - a. _____
 - b. _____
 - c. _____
4. Why are antihistamines not a preferred first-line treatment for insomnia in elderly people?

Answers

(1) cholestasis, uremia, hematologic malignancy (Hodgkin lymphoma), (2) cholestyramine, gabapentin (Neurontin), (3) subphrenic abscess, empyema, gastroesophageal reflux disease (GERD), (4) Antihistamines can cause paradoxical central nervous system (CNS) arousal and stimulation in elderly patients.

Pruritus

Definition

Pruritus is a local or generalized itch. It can be a debilitating symptom of primary skin disorders and systemic disease.

Differential Diagnosis

1. Primary skin disease
 - Xerosis (dry skin)
 - Urticaria
 - Contact dermatitis
 - Atopic dermatitis
 - Psoriasis
2. Infectious
 - Dermatophytosis
 - Scabies
 - Pediculosis corporis (lice)
3. Systemic
 - Uremia
 - Cholestasis
 - Multiple sclerosis
 - Thyrotoxicosis
 - Diabetes
 - Human immunodeficiency virus infection
4. Malignancy
 - Hodgkin lymphoma
 - Polycythemia vera
 - Mycosis fungoides (cutaneous T-cell lymphoma)
 - Non-Hodgkin lymphoma
 - Leukemia

Assessment

Perform complete history and physical examination. Elucidate exacerbating or relieving factors. Differentiate primary skin findings from secondary excoriations due to scratching. If pruritus is thought to be a manifestation of systemic disease, look for stigmata of chronic liver or renal disease, lymphadenopathy, splenomegaly, or thyroid enlargement.

Treatment

Treat the underlying systemic or skin disease.

NONPHARMACOLOGIC

- Avoid irritants (detergents, scratchy clothing, pet dander)
- Avoid scratching—More scratching exacerbates the itch and creates a scratch-itch cycle.
- Avoid dry skin—Use humidifier, avoid very hot bathing, and keep skin cool.
- Use skin moisturizer or petroleum jelly (Vaseline).

PHARMACOLOGIC

- Antihistamines: Can cause sedation, urinary retention, or paradoxical CNS arousal in elderly; use with caution.

Diphenhydramine (Benadryl)	25-50 mg IV/po/IM q 4-6 h
Hydroxyzine (Vistaril)	25-100 mg po q 6-8 h
Selective peripheral H ₁ blocker (less sedation) Loratadine (Claritin)	10 mg po daily
fexofenadine (Allegra)	180 mg po daily

- Cholesterol binder: For uremia, cholestasis, polycythemia vera

Cholestyramine (Questran)	2-8 mg po bid
---------------------------	---------------

- Antiepileptics: For pruritus refractory to other treatment

Gabapentin (Neurontin)	300-600 mg po tid
------------------------	-------------------

- Topical agents

Camphor/menthol (Sarna lotion)	
Capsaicin cream	
Corticosteroids (for inflammatory itch): hydrocortisone cream 2.5 percent.	

NOTES

Hiccups

Definition

Hiccups (singultus) are the intermittent, involuntary, spasmodic contraction of the diaphragm and muscles of inspiration (intercostals). Hiccups are common and frequently transient. They can become persistent (lasting >48 hours) and rarely intractable (>2 months). Although usually self-limiting, they can be indicative of significant underlying pathology.

Differential Diagnosis

1. Vagus or phrenic nerve irritation

- Pharyngitis
- Head and neck tumors
- Empyema
- Gastric distension
- Subphrenic abscess
- GERD
- Hiatal hernia

2. CNS disorders

- Meningitis
- Brainstem tumors
- Head trauma
- Stroke

3. Toxic-metabolic/drugs

- General anesthesia
- Uremia
- Alcohol
- Diazepam

4. Psychogenic (by exclusion)

- Anxiety
- Stress
- Excessive aerophagia

Assessment

Short-lived bouts of hiccups (lasting <48 hours) do not require extensive investigation. Hiccups lasting longer should be evaluated with a complete history and physical examination; Give attention to drug and alcohol history. Hiccups occurring during sleep point to an organic rather than a psychogenic cause. Adjunctive tests may be warranted to look for signs of infection (complete blood cell count) or a mechanical explanation (chest Xray)

Treatment

Treat the underlying cause, if identified.

NONPHARMACOLOGIC

- Physical maneuvers (interrupt vagal-mediated hiccup reflex arc):
 - Breath-holding
 - Valsalva
 - Breathing into bag
- Hypnosis and acupuncture
- Surgery (for intractable hiccups failing several courses of treatment)
 - Phrenic crush or vagus nerve stimulation

PHARMACOLOGIC

Antipsychotics Chlorpromazine (Thorazine)	25–50 mg po tid or 25–50 mg by IV infusion once
Dopamine antagonists Metoclopramide (Reglan)	10 mg po tid to qid
Muscle relaxants Baclofen (Lioresal)	10–20 mg po bid to tid
Antiepileptic drugs (phenytoin), antidepressants (amitriptyline), and CNS stimulants (methylphenidate) have been reported in case series.	

NOTES

Insomnia

Definition

Insomnia is characterized by the inability to initiate sleep, maintain sleep, or achieve adequate restorative sleep despite ample opportunity and is associated with chronically impaired daytime functioning.

Differential Diagnosis

- Acute insomnia/adjustment insomnia
 - Stress-related
 - Bereavement
 - Anxiety
 - Depression
 - Adjustment disorders
- Inadequate sleep hygiene
- Insomnia associated with medical conditions
 - Dyspnea
 - Cough
 - GERD
 - Nocturia
 - Pain
- Insomnia associated with drugs
 - Caffeine
 - Alcohol
 - Nicotine
 - Bronchodilators
 - Clonidine
 - Cortisone
 - Diuretics

Assessment

Complete history and physical examination. Rule out concurrent medical or psychiatric illness that could be causing insomnia. Pay attention to sleep habits and sleep hygiene.

Treatment

NONPHARMACOLOGIC

- Improve sleep hygiene
- During daytime: avoid naps, awake at same time each day, remain as active as possible, get adequate exposure to sunlight, avoid caffeine, alcohol, and nicotine.
- At nighttime: arrange for same bedtime each night, avoid eating before sleep, do not read or watch television in bed, maintain comfortable environment conducive to sleep—quiet, cool, dark.

PHARMACOLOGIC

(In general, use short courses, lowest effective dose, prescribed intermittently [that is, 3–4 times per week]. Avoid diphenhydramine in elderly people because it can have a paradoxical stimulant effect.)

Benzodiazepines Lorazepam (Ativan) Temazepam (Restoril)	0.5–2 mg po HS 7.5–15 mg po HS (caution with prolonged half-life in elderly patients)
Antidepressants Trazodone (Desyrel)	25–150 mg po HS (can cause orthostatic hypotension)
Short-acting, nonbenzodiazepines Zaleplon (Sonata) Zolpidem (Ambien)	5 mg po HS 5–10 mg po HS

NOTES

Bibliography

Charlesworth EN, Beltrani VS. Pruritic dermatoses: overview of etiology and therapy. *Am J Med.* 2002;113:25S–33S.

Friedman NL. Hiccups: a treatment review. *Pharmacotherapy.* 1996;16:986–995.

Kolodzik PW, Eilers MA. Hiccups (singultus): review and approach to management. *Ann Emerg Med.* 1991;20:565–573.

Rueben DB, et al. *Geriatrics at Your Fingertips.* Belle Mead: Excerpta Medica, Inc. 2000.

Sateia M, Nowell P. Insomnia. *Lancet.* 2004;364:1959–1973.

Yesudian PD, Wilson NJE. Efficacy of gabapentin in the management of pruritus of unknown origin. *Arch Dermatol.* 2005;141:1507–1509.

Yosipovitch G, David M. The diagnostic and therapeutic approach to idiopathic generalized pruritus. *Int J Dermatol.* 1999;38:881–887.

Yosipovitch G, Greaves MW, Schmelz M. Itch. *Lancet.* 2003;361:690–694.

NOTES

Case Studies | Faculty Guide

CASE 1. Pruritus

Objectives

1. Review the differential diagnosis (with emphasis on likely etiologies pertinent to surgical patients).
2. Emphasize that the primary treatment for pruritus is treatment of the underlying condition.
3. Suggest additional ancillary tests that may be helpful in determining the cause of pruritus in a surgical patient.

CASE 2. Hiccups

Objectives

1. Review the differential diagnosis (with emphasis on etiologies pertinent to surgical patients).
2. Understand that primary treatment of hiccups should be treatment of the underlying condition.
3. Differentiate between first- and second-line treatments, as well as pharmacologic and nonpharmacologic remedies, for hiccups.

CASE 3. Insomnia

Objectives

1. Review the differential diagnosis for insomnia.
2. Understand the significant role that psychological or psychiatric factors may have for patients with insomnia who face severe, life-limiting illness.
3. Recommend simple home remedies and behavior alternations that may correct insomnia.
4. Suggest pharmacologic therapies for insomnia that have limited prolonged sedation.

CASE 1. Pruritus

Mr. P. is a 53-year-old patient admitted to the hospital for abdominal pain and jaundice. His direct serum bilirubin level measured 11.3 mg/dL, and further workup revealed cholangiocarcinoma. He is to undergo further testing to ascertain the most appropriate treatment strategy. While in the hospital, his nurse calls in the evening with a report that Mr. P. is complaining of significant itch.

QUESTIONS

1. What is the likely cause of the pruritus? (Need more clinical information [such as bilirubin level] to answer this and the other questions.)
2. What tests, if not already performed, can confirm the cause?
3. What interventions may be necessary to treat the pruritus?
4. While arranging those interventions, what are effective drugs for this and what would be the sequence among the various drugs?

Teaching Points

- Pruritus can indicate serious underlying conditions. Treatment should be aimed at finding an underlying cause and correcting the inciting problem.
- In Mr. P.'s case, his cholangiocarcinoma is likely causing obstructive jaundice. He will require decompression of his biliary system to relieve the obstruction. This is an invasive procedure that may or may not be accompanied by a definitive surgical resection.
- In the meantime, cholestyramine may be a helpful adjunct.

NOTES

CASE 2. Hiccups

Mrs. X. is 52 year-old woman who is recovering from a distal pancreatectomy and splenectomy. On postoperative day 3, she complains of persistent hiccups. Simple maneuvers such as breath-holding and concentration (drinking from the opposite side of glass) have not worked.

QUESTIONS

1. What physical exam findings might help in making the diagnosis?
2. What tests (laboratory or radiology) would help in ascertaining the cause of the hiccups?
3. What would be an appropriate first-line treatment for the hiccups. What agent will you use if that does not work?

Teaching Points

- Hiccups, like pruritus, can be a harbinger of significant pathology in surgical patients.
- Assessment should first focus on identifying a structural cause for the hiccups (in this case, possible subphrenic abscess). A white blood cell count may show leukocytosis, and chest Xray may show a sympathetic left-sided pleural effusion.
- Treatment must address the underlying cause, which might include drainage of the abscess (percutaneously or operatively). Pharmacologic treatments can be helpful as a bridge to definitive surgical treatment or when a cause is never identified.

CASE 3. Insomnia

Mr. H. is a 75-year-old man recently discharged from the hospital after a colon cancer operation. He is returning to the clinic for a postoperative visit to discuss his final pathology report and further treatment plans. His wife died 5 months ago after a long decline due to dementia. Mr. H. tells you that his pain is adequately controlled, but he is not sleeping. He feels tired all day and has trouble falling asleep.

QUESTIONS

1. What additional questions might be helpful in elucidating a cause of the insomnia?
2. How might his insomnia be related to his wife's recent death and his own diagnosis?
3. What information regarding Mr. H.'s lifestyle and sleep habits would be important while assessing his complaint of insomnia?

Teaching Points

- Assessment of insomnia must include a psychiatric history and exploration of psychological factors that could be causing the sleep difficulty (such as anxiety, stress, grief).
- Patients who undergo major life changes may be experiencing abrupt alterations in their routine and sleep hygiene that can exacerbate insomnia.
- Pharmacologic therapies should be selected based on the lowest effective dose and the least likely treatment to cause persistent sedation the following day.

NOTES

CHAPTER 12

Palliative Surgery: Definition, Principles, Outcomes Assessment

“I hope we have taken another good step [gastrectomy] towards securing
unfortunate people hitherto regarded as incurable or, if there should be
recurrences of cancer, at least alleviating their suffering for a time.”

—Theodor Billroth, MD, 1881

Learning Objectives

Attitudes

- Reflects on prior good and bad experiences witnessing or performing surgery on patients with advanced, symptomatic illness.
- Values the role of surgery when applied solely for the relief of symptoms, regardless of its impact on prolonging survival.
- Respects the patient's autonomy and right to understand the nature of the proposed procedure, its expected risks and benefits, and alternative approaches.
- Believes that palliative surgery is one important commitment of whole patient care provided by surgeons.

Knowledge

- Describe five indications for palliative surgery.
- Describe the difference between a noncurative and palliative procedure.
- Describe the considerations in planning a palliative procedure.
- Describe the potential ethical hazards inherent in performing palliative surgery.
- Describe the potential outcomes measures for palliative surgery.
- Describe the use of three adjunct therapies for palliative surgical procedures.

Skills

- Demonstrate how to initiate a discussion about palliative surgery.
- Demonstrate proficiency in gastric resection for a bulky, bleeding (stage IV) neoplasm.
- Demonstrate proficiency in bowel resection and stoma formation.
- Demonstrate proficiency in biliary and enteric bypass procedures.
- Demonstrate proficiency in performance of celiac plexus block during laparotomy.
- Demonstrate proficiency in long-term venous access device (Mediport) insertion.
- Demonstrate proficiency in endoscopic percutaneous gastrostomy (PEG) insertion.
- Demonstrate proficiency in performance of paracentesis.
- Demonstrate proficiency in insertion of Tenkhoff catheter.
- Demonstrate proficiency in performance of tube thoracostomy.
- Demonstrate proficiency in performing palliative mastectomy.
- Demonstrate proficiency in lower extremity amputations.
- Demonstrate proficiency in management of fistulas and complex wounds.

NOTES

Pre/Post Test

1. Describe three indications for palliative surgery.

- a. _____
- b. _____
- c. _____

2. Describe the difference between a noncurative and palliative procedure.

3. List the three main considerations in planning a palliative surgical procedure.

4. Describe two indicators used for measuring palliative surgical outcomes.

Answers

(1) obstruction, hemorrhage, pain, (2) Palliative surgery relieves patient-identified distressing symptoms; noncurative surgery is surgery after which there is residual disease with or without symptom relief, (3) goals and persona of the patient, nature of the disease process, effectiveness of the intervention, (4) PSOS, EROTC

Palliative Surgery

Palliative surgery is as ancient as surgery itself, although it remains an evolving concept because of the changing face of illness, technologic innovation, and developments in the moral and ethical framework within which surgeons operate. The word *palliative* applied to surgery has had an almost pejorative connotation to surgeons because of the specter of failure that haunts us in the face of any incurable illness, despite the fact that incurability is an expected and natural phase of many ailments and surgeons have much to offer patients even in the last stages of illness. Confusion about the definition of palliative surgery has recently been lessened as consensus emerges about the role of surgery in advanced and symptomatic illness. Previously, the term, *palliative surgery* was used to describe a resection with microscopic or gross residual tumor left in situ at the end of the operation or a resection done for persistent or recurrent disease after treatment failure. This confusion runs deep in surgical practice and literature, but will hopefully be dispelled with a clear and consistent definition. The definition of palliative surgery—surgical procedures used with the primary intention of improving quality of life (QOL) or relieving symptoms caused by an advanced disease—that has emerged is consistent with the established principles of nonsurgical palliative care.

Palliative surgery is common in surgical oncology practice, consisting of 10 to 20 percent of all surgery performed. When one considers the palliative nature of numerous vascular, plastic, orthopedic, and ophthalmologic procedures for symptoms stemming from nonneoplastic, progressive, life-limiting diseases (such as chronic renal failure), the percentage could be much higher. As a technical undertaking, the skill set and techniques for performing palliative surgery are no different from those for curative indications. Clinical judgment when performing major palliative surgical interventions is notoriously and appropriately demanding of even the most seasoned clinician. Many of the principles outlined in this chapter have been derived from the experience of these individuals.

Except for the degree of risk, the moral and ethical questions about palliative surgery are no different from those posed by any other medical treatment for this vulnerable population. The primary ethical challenge inherent to palliative surgery is the balancing of the moral duty to

help with the ethical imperatives of nonmaleficence and beneficence. Unchallenged benevolence can undermine autonomy if it masks paternalism and the use of power—a likely possibility for surgeons, who have traditionally been seen as authoritarian and powerful. Other threats to patient autonomy that apply when contemplating any invasive palliative treatment include the following:

- The paucity of scientific outcomes data for many palliative procedures
- Patients' heightened physical, psychological, and social vulnerability
- Misinterpretation about what “doing everything” means
- Lack of knowledge by patients and care providers about less invasive but equally effective alternative treatments
- Pressures from family and other health professionals to “do something”

The increasing availability of palliative care teams provides the opportunity for an interdisciplinary approach to mitigating these pressures on patients, families, and surgeons.

Definitions

Palliative Surgery: A surgical procedure used with the primary intention of improving QOL or relieving symptoms caused by an advanced disease. The effectiveness of palliative surgery is judged by the presence and durability of patient-acknowledged symptom resolution.

Noncurative Surgery: Operations with curative intent in asymptomatic patients that result in residual disease or positive margins.

NOTES

Principles of Palliative Surgery

- Palliation is not the opposite of cure; it has its own distinct indications and goals and should be evaluated independently
- Asymptomatic patients cannot be palliated.
- Palliative surgery is as morally and ethically legitimate as surgery for curative intent.
- Day-to-day surgical decisions are best made in the framework of ethical, scientific, and technical principles.
- The patient or surrogate must acknowledge the personal relevance of the symptom to be treated.
- Meaningful survival expectations should exist before offering surgical palliation.
- Goals must be clearly and honestly defined to patient and family, yourself, the surgical team, and other members of the health care team.

Selection of Procedure

The three main determinants for selecting a procedure include:

- The patient's symptoms and personal goals
- The expected impact of the procedure on QOL, function, and/or prognosis (time)
- Prognosis of the underlying disease (time and functional decline expectations)

Additional determinants include the following:

- Feasibility/availability of nonsurgical options (such as pharmacotherapy, radiation therapy, chemotherapy)
- Reconstructive requirements (such as plastic surgical coverage, wound vacuum device)
- Recovery and rehabilitation requirements
- Surgeon characteristics (such as experience, technical ability)
- Technical considerations (such as an expectation of extensive adhesions)

Patient Assessment for Palliative Surgery

1. Does the patient/surrogate understand the nature and prognosis of the underlying illness?
2. Does the patient/surrogate understand the potential risks/benefits of the proposed surgical intervention?
3. Does the patient/surrogate understand the available nonsurgical options?
4. Can the patient physically tolerate the procedure based on organ system function?
5. Is the expected improvement in quality, function, or time sufficient to warrant the proposed surgical intervention?
6. Does the patient have an advance directive including a designated surrogate decision maker?

Discussing the Surgical Procedure

The discussion with a patient and family members about a palliative procedure requires the same careful preparation that the procedure itself would require. For some patients, the true nature of their illness may not be apparent to them until the purpose and details of an intervention are discussed (see Chapter 12, Delivering Bad News). Gentle probing for the patient's degree of awareness of the medical situation and readiness to proceed with the discussion is no different from the first steps in any operation. The patient should be given the opportunity to have the individuals he or she wants present for the discussion. The discussion preceding a palliative intervention is an extraordinary opportunity to clarify goals of care, adjust future treatment plans accordingly, and deepen the level of trust between the patient and the surgeon. The surgeon should be prepared to make a recommendation in addition to merely providing information. A surgeon who is unwilling to make a recommendation runs the risk of being considered, at best, indecisive and, at worst, abandoning.

NOTES

Anesthesia Issues

Anesthetic considerations are based on the anticipated physiologic impact of the procedure and the anesthetic regimen due to hypoproteinemia and decreased renal, hepatic, and cardiopulmonary reserve. Consideration should be given to perioperative analgesic approaches that would benefit from the anesthesiologist's intervention. Special attention and communication are necessary for patients receiving preoperative opioids to plan for postoperative pain management.

The DNR status for patients undergoing surgery should be specifically addressed before surgery. The American College of Surgeons, the Association of Operating Room Nurses, and the American Society of Anesthesiologists position papers condemn policies requiring automatic cancellation of existing DNR orders for patients undergoing anesthesia, based on the principle of patient autonomy. However, many hospitals and surgical centers have this type of policy. It is imperative to discuss and develop a written plan for resuscitation management options, in the event of cardiopulmonary arrest, with the anesthesiologist and the patient/surrogate, for the intraoperative and the immediate postoperative periods.

Palliative Surgical Procedures

Palliative surgical procedures can be classified into two groups: (1) procedures that directly relieve symptoms and procedures done as part of an interdisciplinary plan for symptom relief, such as a biopsy done to guide radiation therapy; and (2) supportive procedures that guide or enable the delivery of non-surgical palliative treatment.

Palliative surgical procedures for direct symptom control

- Drainage procedures for ascites, pleural effusions, pericardial effusions
- Laparotomy/laparoscopy and bypass or resection for relief of biliary or bowel obstruction
- Resection of tumor (debulking) for relief of pain, constitutional symptoms, control of odor
- Endoscopic interventions for stenting an obstructed lumen, ablation of tumor, hemostasis
- Gastrostomy (PEG) placement for relief of obstruction or hunger
- Definitive management of pleural effusion (VATS)
- Craniotomy for excision of symptomatic metastasis or for hemorrhage
- Fixation of pathologic fracture
- Major amputation for painful, nonviable extremity
- Tumor embolization procedures
- Surgical procedures for metastatic spinal cord compression
- Suprapubic cystostomy for bladder outlet obstruction
- Simple mastectomy (aka toilet)
- Spit fistula
- Tracheostomy (obstructing head and neck cancer)

Palliative support procedures

- Biopsy procedures to guide palliative treatment
- Vascular access procedures for medication administration, dialysis, and parenteral nutrition
- Gut intubation procedures for feeding (PEG)

NOTES

Complications, QOL, and Outcomes Measurement

The complication rate for palliative surgical interventions is high and not limited to major procedures. Palliative procedures contributed to 36 percent of the total annual 30-day operative mortality in one major cancer center where it was also determined that a major postoperative complication reduced the probability of symptom resolution to 17 percent. Complications occurred with comparable frequency regardless of surgical subspecialty in this survey.

There is currently no validated instrument for measuring QOL outcome for palliative surgical procedures. Previously, mortality, morbidity, performance status (Karnofsky Performance Status), or functional measures such as ability to swallow have been used to measure palliative surgery outcomes. The European Organization for Research and Treatment of Cancer (EORTC) QLQ-C30 Core Module and Functional Assessment of Cancer Therapy (FACT) have been used for surgical patients but have not been adapted and prospectively evaluated for the extensive repertoire of palliative surgery. The absence of a postoperative complication requiring hospitalization has been used as part of a proxy measurement for QOL following palliative surgery.

The Palliative Surgery Outcome Score (PSOS) is a prospective measure of the impact of palliative surgery. It is calculated by using the following equation:

$$\frac{\text{Number of Symptom-free, Nonhospitalized Days/}}{\text{Number of Postoperative Days of Life (up to 180 Days)}}$$

Symptom-free denotes the symptom intended for treatment and free of major complications. **Hospitalized** denotes days hospitalized for the palliative operation and any additional days to monitor surgical complications or recurrent symptoms.

A PSOS value of 0.7 was identified by patients and families who had good to excellent palliation as an acceptable outcome score. With increasing exposure to social science research methods, better prospective measures for QOL outcomes for palliative surgery should emerge.

Bibliography

- Cady B, Miner T, Morgentaler A. Part 2: surgical palliation of advanced illness: what's new, what's helpful. *J Am Coll Surg*. 2005;9(2):281–285.
- Demme RA, Singer EA, Greenlaw J, et al. Ethical issues in palliative care. *Anesthesiology Clin N Am*. 2006;24:129–144.
- Dunn GP, Johnson AG. *Surgical Palliative Care*. New York, NY: Oxford University Press; 2004:1–267.
- Easson AM, Asch M, Swallow CJ. Palliative general surgical procedures. *Surg Oncol Clin N Am*. 2001;10(1):161–184.
- Hofmann B, Håheim LL, Søreide JA. Ethics of palliative surgery in patients with cancer. *Br J Surg*. 2005;92:802–809.
- McCahill L, Ferrell B. Palliative surgery for cancer pain. *West J Med*. 2002;176:107–110.
- Wagman L, ed. Palliative surgical oncology. *Surg Oncol Clin N Am*. 2004;13:401–547.
- Weissman DE. Decision making at a time of crisis near the end of life. *JAMA*. 2004;292:1738–1743.

NOTES

Case Study | Faculty Guide

Objectives

1. Describe the assessment of a patient for whom palliative surgery is being considered.
2. Describe the measures taken to ensure that the consent process is truly informed.
3. Describe perioperative anesthesia considerations for a major palliative procedure.
4. Describe the assessment for the efficacy and success of a palliative operation.

Teaching Points

- Resist the temptation of centering the discussion on the surgical procedure rather than the overall goals of care. The procedure is secondary to the goal of care, not the other way around.
- Harness the moment of discussing surgery to address other fears, beliefs, and goals.
- Palliative surgery is an interdisciplinary process—the role of the anesthesiologist is legally and ethically neither superior nor subordinate to the role of the surgeon.
- Objective outcomes measures for palliative surgery have been described for gastrectomy.

Case Study

B.T., a 78-year-old single man who is a retired history professor is admitted to the emergency department with a history of a 17-lb weight loss and early postprandial satiety during the previous month. The day of admission, he has a single, large hematemesis. He is hemodynamically stable after transfusion of 2 U of packed red blood cells. Upper endoscopy shows a bulky, friable mass in the gastric body. It is not actively bleeding. Computed tomography of the abdomen demonstrates a 12-cm mass in the gastric body with thickening of the gastric wall in the proximal antrum. The gastroesophageal junction appears normal. Several enlarged peripyloric nodes are present. There are two lesions in the left lobe of the liver consistent with metastases. Biopsy of stomach taken at endoscopy shows a poorly differentiated adenocarcinoma of the stomach. He tells you he suspected “something was going on,” and when he learns the diagnosis, he states he will consider treatment but does not want to suffer or “prolong the inevitable.”

QUESTIONS

1. How do you initially respond to his statements? Emotionally or scientifically?
2. What medical, psychosocial, and spiritual information would be relevant before selecting treatment?
3. How would you frame the discussion if the patient decides against surgical intervention?
4. What alternatives to gastric resection could you recommend?
5. Describe the approach to discussion you will have when obtaining his consent for a gastric resection.
6. Before surgery, the anesthesiologist says he will not give anesthesia unless the patient cancels his DNR order. How would you handle this development?
7. How you would measure a successful outcome of palliative gastrectomy?

NOTES



CHAPTER 13

Pediatric Palliative Care



Learning Objectives

Attitudes

- Recognize the value of specialists and members of the interdisciplinary team to collaborate in the management of children and their families.
- Reflect on the impact of caring for seriously ill children and their families.

Knowledge

- Describe basic principles and goals of pediatric palliative care.
- Describe developmentally appropriate methods to recognize, assess, and initiate therapy for multiple sources of suffering.
- Acknowledge the impact of a do-not-attempt-resuscitation (DNAR) order in the care of children.
- Understand principles of decision making with children and their families.
- Know when to refer the child and family for specialist care.

Skills

- Demonstrate the management of procedural, acute, and chronic pain in children.
- Develop a plan of care for managing care-related anxiety in children of different developmental stages.

NOTES

Pre/Post Test

1. In pediatrics, the standard for pain assessment in children is:
 - a. the FLACC pain score.
 - b. the presence of vital sign changes.
 - c. the absence of sleep and play.
 - d. patient self-report.
 - e. parental report.
2. When a child with a DNAR order undergoes surgery, in addition to reviewing institutional policies, the practitioner should:
 - a. rescind the DNAR order for the period surrounding the surgery.
 - b. honor the DNAR order even if there are complications with anesthesia or surgery.
 - c. avoid all surgeries because surgery is invasive and contrary to the wishes of someone with a DNAR order.
 - d. review the intent of the order to help the care team members understand what they should do if the child has a complication with surgery or anesthesia.
3. TRUE or FALSE: A child with a DNAR order should not receive invasive procedures because the goal of care is comfort measures.
4. TRUE or FALSE: Collaborating with specialists—such as child life therapists, social workers, psychologists, palliative care specialists, and pediatricians—can be very useful even in the day-to-day assessment and communication with children and their families.
5. TRUE or FALSE: The life of a child is precious, and resuscitation should be continued if there is any hope of restoring vital signs.
6. The most effective approach to treating pain in children is by:
 - a. the ladder, by the clock, by the mouth, and by the child.
 - b. starting empiric therapy for anticipated pain.
 - c. aggressively treating procedure-related pain.
 - d. frequently assessing and asking in words the child can understand whether he or she has pain.
 - e. all of the above.

Answers:

(1) d, (2) d, (3) false (DNAR only describes wishes in the event of cardiopulmonary arrest. Comfort measures describe a different set of goals that are associated only with the terminal stage of illness.), (4) true (Practitioners with experience working with children can be very helpful, especially when communication has broken down or pain persists despite standard approaches to therapy.), (5) false (Although aggressive resuscitation may restart circulation in a child, the long-term outcome should be considered in all situations, adult or pediatric), (6) e

Pediatric Palliative Care

Approximately 55,000 infants, children, and adolescents die each year in the United States of complications of prematurity, congenital defects, injuries, malignancies, and a wide variety of other illnesses.¹⁻³ Of these children, most will die in a hospital, with a large proportion cared for in a hospital during the days or weeks before their death.⁴ During the past 30 years, it seems that significantly more children are living their lives with a life-threatening condition. This chapter addresses how these children can be cared for using the principles and practices of palliative care.

Goals of Pediatric Palliative Care

Pediatric palliative care includes any intervention that focuses on reducing the morbidity of illness, slowing the progression of disease, and improving quality of life.⁵ In short, palliative care is about finding ways to improve life in difficult circumstances. Although palliative care principles are especially important in the care of dying children, the same principles apply to all children with complex or serious illness, regardless of prognosis.

The goals of palliative interventions are as follows:

1. Relieve suffering (physical, psychological, spiritual, and social), including the treatment of pain and other distressing symptoms
2. Provide psychosocial and spiritual care to children and their families
3. Provide interventions aimed to help the child and family live with as much quality as possible
4. Provide interventions aimed at helping the child and family cope with grief and bereavement
5. Continue interventions after death aimed at rehabilitating and facilitating bereavement in families, ensuring they remain functional and intact

To achieve these goals, every practitioner should:

1. Understand the challenges faced by children and their families when palliative care is needed.
2. Learn how to communicate effectively with children and their families.
3. Demonstrate how to use developmentally appropriate methods to recognize, assess, and initiate therapy for multiple sources of suffering.
4. Know when to refer the child and family for more definitive management.

Although each individual patient may have significant complexities to care, the approach to pediatric palliative care can be simplified. Following the approach in Figure 1 can help organize the practitioner's approach to care and help determine when a specialist's involvement is necessary.

NOTES

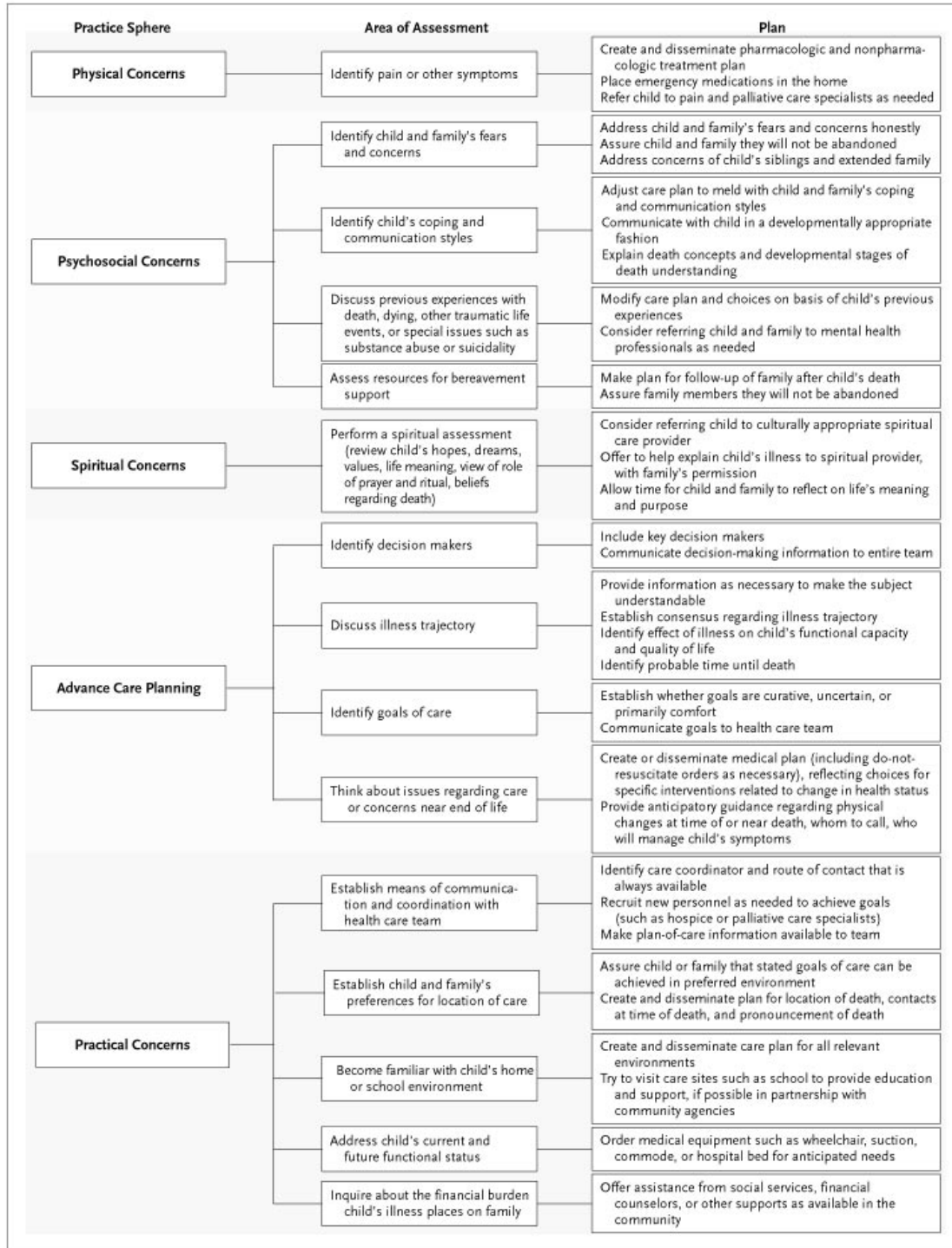


FIGURE 1. Essential elements in the approach to pediatric palliative care. Reprinted with permission from Himelstein BP, Hilden JM, Boldt AM, et al. Pediatric palliative care. *N Engl J Med.* 2004;350(17):1754.

NOTES

Adult vs Pediatric Palliative Care

Although similar in principles, goals, and even approach to care, there are some major differences between adult and pediatric palliative care⁶:

- Death during childhood is relatively rare.
- Physiologic and cognitive developmental differences affect assessment, treatment, communication, and decision making.
- Many childhood illnesses offer an unclear prognosis and inherent uncertainty of disease trajectory.
- Cultural and societal norms regarding care are based on the expectation that children do not die.
- Decision making for dependent, nonautonomous children, is associated with significant legal and ethical issues.

Hospice

Hospice agencies are valuable resources to children, families, and care providers because they can provide the following resources to children, families, and practitioners:

1. 24-hour availability for in-home assessment and management for distressing symptoms
2. Psychosocial, spiritual, and decision-making support for the child and family
3. Grief and bereavement care for the family after the child dies

Misconceptions about hospice can limit families' and practitioners' acceptance of this resource.

Misconception 1: Enrolling with hospice means that the medical team is giving up on the child, and the child is going home to die. To the contrary, hospice services can be used simultaneously with certain measures of life-sustaining intent, such as platelet transfusions and palliative chemotherapy.

Misconception 2: A DNAR order is required to enter hospice care. In fact, a hospice agency is not supposed to use DNAR status as a condition of enrollment.

Misconception 3: Once children enroll with hospice, they are not allowed to return to the hospital. To the contrary, in keeping with the Medicare guidelines, a patient may return for inpatient hospital care if problems cannot be managed successfully in the home. A child may disenroll from hospice and return to hospice care at a later date (see Hospice Module).

NOTES

Interdisciplinary Care

Assessment and management of children with serious and/or life-threatening or life-limiting conditions and their families is complex. Care is best provided by an interdisciplinary team that includes the pediatric surgeon, primary pediatrician, a pain or palliative care specialist, and a psychologist or a psychosocial specialist (for example, social worker or child life specialist). Collaborating with these specialists will enhance the practitioner's ability to care for the children and their families and can improve the lives of the children and their families.

Goals of Care and Do-Not-Resuscitate Orders

When considering an intervention, the benefits, risks, and burdens must be considered, including the short- and long-term effects on the child's quality of life.

Goals of care: At the diagnosis of many illnesses, the goals of care are likely to include aggressive curative and restorative measures. This focus may change as the likelihood of survival decreases, burden of illness increases, or the quality of life worsens. The family must be supported in deciding what the focus of care should be. Goals of care need to be reevaluated frequently, especially at any major change in condition.

Resuscitation after cardiopulmonary arrest: The potential outcome must be considered during resuscitation after cardiopulmonary arrest. In certain situations, as in acute trauma, resuscitation hopes to restore a child to previous functional status—clearly a good outcome. However, some practitioners feel pressed to continue resuscitation even after hope for a good outcome has passed. While every child and each situation are unique, the long-term benefits must be considered even in this acute situation.

DNAR and Do-Not-Intubate (DNI) orders: Resuscitation after cardiopulmonary arrest is a medical intervention, and, like all medical interventions, there are situations in which a resuscitation is not in the best interest of the child. DNAR orders are becoming more common in pediatrics.^{7,8} In practice, a DNAR order is not specific to a set of orders, and the specifics of limitations need

to be spelled out in the medical record. It is important to note that DNAR and DNI orders do not preclude life-sustaining, restorative, or curative measures.

DNAR in the perioperative period: Occasionally, a child with a DNAR order will require a surgical procedure, which may necessitate some features that are limited by the DNAR order. In this setting, it may be appropriate to rescind the DNAR order for the perioperative period. In other situations, it may also be appropriate to maintain the limitations despite events in the perioperative period.⁹ Most important, the surgical, anesthesia, and postoperative care team must understand the intentions of the child and family and not merely follow the specifics of the order.

Comfort measures at the end of life: In some children with life-threatening illnesses, the burden of disease and poor quality of life outweigh the potential benefit of longer duration of life. In these situations, a family may choose to pursue comfort measures only and forgo any life-sustaining therapy. This situation differs from a DNAR order in that the focus of care may also include explicit limitations on invasive procedures, withdrawal of life-sustaining therapies, withholding of artificial nutrition and hydration, and a focus on ensuring that the child is in no discomfort.

NOTES

Symptom Management

Alleviating suffering of any type is the cornerstone of palliative care, including aggressive, empiric therapy and frequent, developmentally appropriate assessment. Children do not separate the physical and emotional nature of suffering and may have extreme anxiety due to anticipated pain or other symptoms.

NONPHARMACOLOGIC THERAPIES FOR PAIN AND OTHER SYMPTOMS

Nonpharmacologic therapies are most helpful when used in conjunction with pharmacologic options. Examples include the following:

- Guided imagery
- Distraction and relaxation
- Massage
- Acupuncture and acupressure
- Play

The expertise of a child-life specialist (available in many children's hospitals) and pain or palliative care specialist should be used.

Effective tools to managing anxiety associated with care and procedures include the following:

- **Share control:** Give the child some control over procedures such as giving the child a choice about the arm from which a blood sample will be drawn.
- **Distraction and relaxation:** Distraction (focusing the child's mind on something else such as a toy) and relaxation (as simple as deep breathing) can also help ease the anticipatory anxiety of many procedures.

Role of parent: Teach the parent skills in distraction and relaxation to help the child cope with symptoms and procedures.

Referral to specialist: When the standard approach to therapy is not sufficient to control symptoms, the child should be referred to a pain or palliative care specialist.

Pain

In general, the principles of pain management are similar for children and adults. Please refer to the chapter on pain management for more details. There are, however, some clear differences, including the following:

- Changing physiology with age
- Initial drug dosing based on body weight in children
- Assessment based on developmental and cognitive ability in children

PERCEPTION OF PAIN BY CHILDREN

Children interpret pain based on the following factors¹⁰:

- Age and cognitive ability
- Previous experiences with pain
- Relevance of pain (such as "Has the cancer returned?")
- Expectations for recovery and pain relief
- Ability to control the pain themselves

NOTES

ASSESSMENT OF PAIN

In general, there are four principles in assessing pain in children:

1. The patient's self-report of pain is the "gold standard" (parental report, physiologic indicators, and behavioral indicators are unreliable).
 - Most young children are only able to report their pain at the moment and not levels of pain they had in the past.
2. Ask the child in terms he or she understands. Do not wait for complaint.
3. Assessment must be developmentally appropriate.
4. Reassess frequently and react expediently.
 - Times when a child is at risk for pain:
 - i. After procedures: Institute effective therapy plan if pain is anticipated or is poorly controlled.
 - ii. When medications are wearing off: Increase the dose, shorten the time between doses, or add or change the medication if pain is poorly controlled.
 - iii. At peak effect of medication: Increase the dose if pain is poorly controlled.

Total pain: Total pain is the theory that pain is not just physiologic but also has spiritual, psychological, and social components.¹¹ These aspects of pain often are recognized only when it seems that appropriate therapy is not managing pain. Using the skills of a social worker or a palliative care specialist can help recognize sources and management options in these situations.

DEVELOPMENTAL ASSESSMENT TOOLS

The assessment tools in the following list can be used to assess physical pain in the different age groups. When using these assessment tools, consider the following:

- Whatever assessment method is chosen, the same method should be used for reassessment.
- These tools were validated for cognitively intact children in postprocedural pain.

Neonate: The **CRIES scale** measures the degree of Crying, Required oxygen, Increased vital signs (heart rate and/or blood pressure), Expression (for example, grimace), and Sleeplessness.¹²

Infant and Toddler: The **FLACC Pain Assessment Tool** measures the following categories^{13,14}:

Face	degree of grimace
Legs	degree of restlessness or tension
Activity	degree of agitation
Cry	degree of crying
Consolability	amount of physical consoling needed to comfort child

School-aged children: The **Faces Pain Scale** uses visual images that represent levels of pain. The practitioner grounds the child by describing that one of the faces shows a child in no pain whereas the face on the other end shows a child in the worst pain imaginable. The child then points to the face that represents the amount of pain he or she is having.¹⁵ This tool is designed to help a child report pain and is not meant for use in measuring the child's grimace or expressions of pain.

Age 7 years or older: A numeric scale, in general, can be used by children 7 years old and older. (for example, rating pain on a scale of 1 to 10 with 10 being the worst).

Cognitively impaired children: Extrapolate one of the preceding tools based on the developmental ability of the child. The FLACC pain assessment tool can be especially helpful.

NOTE: Children with *chronic pain* rapidly adapt and may not show all of the features in these tools, making them less reliable.

NOTES

MANAGEMENT OF PAIN

The first step in treating any pain symptom is to consider treating the underlying pathology.

Use the four principles of the World Health Organization (WHO) assessment method¹⁶:

By the ladder	<p>Analgesics should be escalated in a stepwise approach (adapted from the WHO criteria)</p> <p>STEP 1: For mild pain, start a nonopioid analgesic (nonsteroidal anti-inflammatory drug [NSAID] or acetaminophen); consider effective adjuvant therapy.</p> <p>STEP 2: If pain worsens or persists, change to a low dose opioid (such as low dose morphine); consider effective adjuvant therapy and continuing the nonopioid analgesic.</p> <p>STEP 3: If pain worsens or persists, change to higher dose opioid (such as high dose morphine); consider effective adjuvant therapy and continuing nonopioid analgesic.</p> <p>STEP 4: Continue escalation until the patient is free of pain.</p>
By the clock	Analgesics should be scheduled with availability of rescue doses.
By the mouth	Analgesics should be given by the least invasive route.
By the child	Analgesia should be based on the individual child’s circumstances.

Procedure-related pain: Pain relates to procedures is unique because it can be easily anticipated and even prevented. Inadequate pain control in this setting has been associated with increased morbidity and mortality.^{17,18}

Management of pain for minor procedures includes the following strategies:

- **Sucrose and the act of sucking¹⁹:** For minor procedures in infants younger than 3 months
- **Topical analgesia (such as EMLA):** Used to decrease the pain associated with procedures that puncture the skin (for example, obtaining venous blood samples, intravenous line placement, and intramuscular and subcutaneous injections)
 - **Buffered lidocaine infiltration:** In appropriate locations, buffer lidocaine with bicarbonate (9:1 ratio) to decrease the sting associated with the infiltration.
 - **Conscious sedation:** Requires appropriate experience and monitoring but can mitigate the pain associated with more invasive procedures

Breakthrough pain: Breakthrough pain is pain that “breaks through” despite scheduled doses of an analgesic because of an insufficient dose, dosing that is too infrequent, or worsening of the disease or illness. Rescue doses of the analgesic should always be available.

NOTES

APPROACH TO RESCUE ANALGESIC DOSING

1. TYPE: Same opioid offered on an as-needed basis
2. FREQUENCY: Based on the route and time to peak effect
 - **Oral:** Every hour
 - **Subcutaneous:** Every 30 minutes
 - **Intravenous:** Every 15 minutes
3. DOSE: Based on the scheduled dosing
 - **Daily requirement:** 5% to 15% of the total amount in a 24-hour period
 - **Infusions:** 50% to 200% of the hourly dose
 - **Scheduled boluses:** 25% to 50% of the every 4-hour dosing equivalent
4. REEVALUATION: Increase the scheduled opioid if the child is requiring frequent rescue dosing by either increasing the dose or decreasing the frequency

Incident pain: Incident pain is pain that is typically short-lived and occurs with movement.

APPROACH TO ANALGESIC DOSING

1. Anticipate pain, such as nursing care or trips to the bathroom.
2. Provide as-needed medication when movement is anticipated.
3. Use fast-acting analgesics with a short half-life (for example, transmucosal preparations of fentanyl).

SPECIAL CONSIDERATIONS

Neonates (children younger than 3 months): Neonates and premature infants may have an exaggerated sense of pain.²⁰ They are also at an increased risk of respiratory depression.²¹ The approach to dosing is as follows:

1. The initial dose of an opioid should be about 30% of that for older children.
2. Reassessment and titration are then very important.

Opioids to Avoid in Pediatrics

Fixed combination products: Titrating the opioid to treat pain becomes difficult owing to side effects of the nonopioid.

Specific opioids with toxic metabolites: Many opioids have active metabolites with long half-lives. Some of these metabolites (for example, metabolites of propoxyphene and meperidine) are neurotoxic and should be avoided in pediatric patients.

NOTES

OPIOID ROTATION

Occasionally, dose-related side effects limit the use of opioids. In these circumstances, improved pain control with fewer side effects may be accomplished by switching to a different opioid.²² Although this rotation is very effective in managing persistent side effects, it should be avoided because it risks incomplete pain control during the period of rotation.

MANAGEMENT OF THE TOXIC EFFECTS OF OPIOIDS²³

Constipation: All opioids cause constipation. Proper management should include prophylactic therapy (see “Constipation” in the “Nonpain Symptoms” section).

Nausea and vomiting: Nausea and vomiting associated with the initiation of opioids often resolves after several days but may last weeks. During this period, the patient may receive benefit from ondansetron or reglan. If severe, rotating to another opioid may show benefit. Constipation associated with the long-term use of opioids, however, can lead to nausea, the constipation must be relieved.

- **Pruritis:** Pruritis is often interpreted by the child and family as an allergic reaction. This complaint is more often a side effect that will likely resolve after several days. In that time, the child may benefit from diphenhydramine or hydroxyzine.
- **Fatigue:** This side effect often decreases after a few days. If the fatigue is persistent or intolerable, the most effective therapy is rotating the opioid.
- **Delirium:** Delirium, or even simple confusion, is less prevalent in pediatrics and most commonly occurs when a child is receiving multiple medications or in severe illness. If present and caused by the opioid, the best management is rotation of the opioid or a trial of a decreased dose of the same opioid.
- **Myoclonus:** Myoclonus is often only seen in patients receiving very high doses of opioids due to accumulation of metabolites. Treatment includes benzodiazepines and muscle relaxants or rotation of the opioid.

- **Respiratory depression:** Pain itself can cause alterations in breathing patterns that, when relieved, give the perception of a decreased respiratory drive. Although very rare when opioids are dosed appropriately, respiratory depression is preceded by sleepiness, decreased consciousness, decreased respiratory rate, and, finally, apnea. Once identified, this side effect can often be managed by providing respiratory support, decreasing the dose, and waiting for resolution. Rarely is an opioid antagonist (such as naloxone) necessary, although it can be used with extreme caution in severe cases.
- **Urinary retention:** Although urinary retention is not common, specific interventions include external bladder pressure, intermittent bladder catheterization, and adding bethanechol to stimulate bladder contraction. If ineffective, low dose nalbuphine or rotating the type of opioid can be considered.

NOTES

ADJUVANT MEDICATIONS

Adjuvant medications are used in conjunction with standard analgesics in an effort to provide a more directed approach that is specific to the pain the child is experiencing.

1. Determine the type of pain that the child is experiencing (Table 1)
2. Choose medications that:
 - Are directed at the specific type of pain.
 - Have limited side effects.
 - May also provide beneficial side effects (such as giving a medication that causes sleepiness at night to a child having difficulty sleeping).

Table 1 is a brief description of some causes of pain and medications to consider.

Type	Cause	Medication choices	Special considerations
Somatic	Inflammation or damage to tissue impacting peripheral nociceptors	Anti-inflammatory agents (NSAIDs and steroids)	
Bone	Somatic pain occurring with infiltration of bone marrow or focal infiltration or injury of the bone	Anti-inflammatory agents (NSAIDs and steroids); consider methadone as primary opioid if prolonged	Can be refractory to standard therapy; referral to a pain or palliative care specialist should be considered early
Neuropathic	Dysfunction of the central or peripheral nervous system experienced as a burning, pins-and-needles, or sudden, sharp and shooting pain	Topical lidocaine, methadone, tricyclic antidepressants, and anticonvulsants (such as gabapentin and carbamazepine)	Can be refractory to standard therapy; referral to a pain or palliative care specialist should be considered early
Visceral	Pain elicited through visceral organ nociceptors experienced as poorly localized or referred discomfort	Steroids	Treating the primary problem may be the only effective therapy

Steroids: Steroids can have a profound effect on pain and nonpain symptoms, most notably by decreasing inflammation and subjectively increasing energy levels. These medications must be used with caution, however, because they may have significant and severe long-term side effects, short-lived beneficial effects, and profound effect on the primary illness.

NOTES

Nonpain Symptoms

Nausea and vomiting: Nausea can be triggered by distention of or injury to abdominal viscera or by direct stimulation of the parts of the brain associated with nausea (that is, chemoreceptor trigger zone, vestibular apparatus, or the vomiting center). Table 2 provides a list of some common causes of emesis and potential symptom management choices after the specific cause is addressed. (Refer to the chapter on nausea for possible causes and therapies that may be beneficial.)

Source	Medication choices
Toxic effects of drugs or biochemical abnormality	Odansetron
Anxiety or anticipatory	Lorazepam
Movement	Scopolamine
Gastrointestinal obstruction (noncomplete or functional)	Metaclopramide
Gastritis	Protective measure (sucralfate or zantac)

When a single drug regimen is not effective, a second agent with a different mechanism and location of action should be used.

SPECIAL CONSIDERATIONS

Steroids: Steroids are often very helpful in short-term treatment of nausea and vomiting for selected patients and conditions. As mentioned, they should be used with caution.

CONSTIPATION

Constipation is common symptom due to medications, decreased fluid intake, slowed intestinal motility, and decreased physical activity. Preventive measures and frequent assessment of the stooling pattern are the best approach to management. If a single drug regimen is not effective, medications with differing mechanisms should be used together. The following provides an approach to prevention and management:

Step 1: Prevention → Start a bowel stimulant (Senna) in at-risk children, including children treated with opioids.

Step 2: Escalation → Titrate dose of stimulant to effect, and consider adding stool softener (docusate [Colace]) or an osmotic agent (lactulose [Cephulac, Chronulac]). All of these agents may be titrated to effect. Polyethylene glycol 3350 (MiraLAX), a stool softener that can be titrated to effect, can be very useful for prevention and moderate to severe constipation but should be used only for patients who can reliably take the required 4 to 8 oz of water per dose. If constipation is severe, these oral agents may cause severe cramping, and rectal medications for acute management should be considered.

Step 3: Treatment failure, severe cramping, or severe constipation → Evaluate for obstruction and impaction. If none is found, attempt rectal glycerin suppositories (up to two doses) and then Fleet enemas (up to three doses). Severe cases may require more invasive measures, and collaboration with a pediatric specialist is appropriate.

ANXIETY

Acute and chronic anxiety occur commonly in children with life-threatening illnesses and can complicate the management of other symptoms. The most effective treatment of anxiety is addressing the specific cause. Key issues in diagnosis and management include the following:

Prevent the pain of painful experiences:

Children will anticipate pain from procedures and side effects from medications. Effective empiric therapy can mitigate this anxiety.

Manage physical symptoms: Prompt, aggressive, and effective symptom management can mitigate anxiety.

Avoid separation: Separation from family can be extremely distressing to the child and family. Separation from important family members should be limited as much as possible.

Improve physical functioning: Because physical functioning is often limited as a result of disease progression, every effort should be made to improve function. This improvement may be achieved by treating pain, fatigue, and nausea and by providing physical aids such as walkers or wheelchairs and home nursing to help with activities of daily life.

NOTES

Teach cognitive strategies: Helping the child and family gain mastery of the illness by communicating effectively and teaching the child and family coping strategies, such as guided imagery in the treatment of pain, can facilitate their participation in the care plan and reduce anxiety.

Pharmacotherapy: If the aforementioned interventions prove ineffective or inappropriate, medications may be used in severe situations. The most commonly used anxiolytics for this indication are the benzodiazepines, including oral or intravenous lorazepam or diazepam.

Communication

FAMILY MEETINGS, DELIVERING BAD NEWS, AND ADVANCED CARE PLANNING

In general, the approach to communication is not significantly different in pediatrics. However, special consideration should be applied in deciding who participates in these meetings and, ultimately, who participates in medical decision making. Although not always perfect, a good rule of thumb should be the following.

1. Determine the decision maker who is in the best position to represent the best interests and wishes of the child, usually the parent.
2. Consider the role of the child: Always ask the parents what role they would like the child to play. In situations in which an older child is not allowed to participate in any way, the practitioner should elicit the help of the psychosocial team, (such as social worker or palliative care team) to help assess the situation.

PREDICTING TIMING OF DEATH

The timing of this stage of life can be very unpredictable. Concrete estimates of when a child is going to die are often wrong and can lead to distress in the family. Although honesty and a best guess are helpful, the family must understand the inherent unpredictability in these estimates. For example, for a child expected to die in a couple of weeks, the situation can be addressed by saying, “I am worried that she only has a few weeks to live; however, we will have to see how things go, as it could be days or even months. We will continue to talk about this, and I will tell you when I think my estimate is changing.”

NOTES

Summary

Despite dramatic improvements in clinical medicine, death during childhood remains a persistent reality. Addressing the physical, psychosocial, spiritual, and social suffering associated with this reality is a compelling responsibility of all care providers. The people focused on curative and restorative measures can improve that provision by also addressing palliative measures. Addressing suffering of all kinds can and should occur in all phases of illness, even when the focus is on cure.

Other Resources

FOR FAMILIES

- McGrath PJ, Finlay GA, Ritchie J, et al. *Pain, Pain, Go Away: Helping Children With Pain*. 2nd ed. 2003. http://rch.org.au/emplibary/anaen/pain_go_away.pdf. Accessed January 2009.

FOR PRACTITIONERS

Pediatric palliative care

- Doyle D, Hanks G, Cherny N, et al, eds. *Oxford Textbook of Palliative Medicine*. 3rd ed. New York, NY: Oxford University Press; 2005.
- Goldman A, Hain R, Liben S, eds. *Oxford Textbook of Palliative Care for Children*. New York, NY: Oxford University Press; 2006.
- Carter BL, Levetown M, eds. *Palliative Care for Infants, Children, and Adolescents*. Baltimore, MD: Johns Hopkins University Press; 2004.
- Kang T, Munson D, Klick J, eds. Pediatric palliative care. *Pediatr Clin North Am*. 2007; 54 (entire issue).
- Kang T, Hoehn KS, Licht DJ, et al. Pediatric palliative, end-of-life, and bereavement care. *Pediatr Clin North Am*. 2005;52(4):1029–1046, viii.
- Hutton N LM, Frager G, eds. *UNIPAC Eight: The Hospice and Palliative Medicine Approach to Caring for Pediatric Patients*. 3rd ed. New Rochelle, NY: Mary Ann Liebert Publishers, Inc: 2008. UNIPAC Book Series; vol 8.

Procedure-related pain

- Boston Medical Center. PainFree pediatrics: Pharmacologic methods for relieving procedural related pain. Boston Medical Center Web site. <http://www.bmc.org/pediatrics/special/PainFree/Paindrugs.htm>.

Grief and bereavement

- Worden J. *Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner*. 2nd ed. New York, NY: Springer-Verlag; 1991.

NOTES

References

- Arias E, MacDorman MF, Strobino DM, et al. Annual summary of vital statistics: 2002. *Pediatrics*. 2003;112(6 pt 1):1215–1230.
- Himmelstein BP, Hilden JM, Boldt AM, et al. Pediatric palliative care. *N Engl J Med*. 2004;350(17):1752–1762.
- US Department of Health and Human Services HRaSA. Child Health 2007. In; 2007.
- Feudtner C, DiGiuseppe DL, Neff JM. Hospital care for children and young adults in the last year of life: a population-based study. *BMC Med*. 2003;1:3. doi:10.1186/1741-7015-1-3.
- American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care. Palliative care for children. *Pediatrics*. 2000;106(2 pt 1):351–7.
- Hutton N LM, Frager G, eds. *UNIPAC Eight: The Hospice and Palliative Medicine Approach to Caring for Pediatric Patients*. 3rd ed. New Rochelle, NY: Mary Ann Liebert Publishers, Inc; 2008. UNIPAC Book Series; vol 8.
- Kipper DJ, Piva JP, Garcia PC, et al. Evolution of the medical practices and modes of death on pediatric intensive care units in southern Brazil. *Pediatr Crit Care Med*. 2005;6(3):258–263.
- Feudtner C, Conner S. Epidemiology and health services research. In: Carter BL, Levetown M, eds. *Palliative Care for Infants, Children, and Adolescents*. Baltimore, MD: Johns Hopkins University Press; 2004:3–22.
- Fallat ME, Deshpande JK. Do-not-resuscitate orders for pediatric patients who require anesthesia and surgery. *Pediatrics*. 2004;114(6):1686–1692.
- McGrath PA BS. Pain control. In: Doyle D, Hanks G, Cherny N, et al, eds. *Oxford Textbook of Palliative Medicine*. 3rd ed. New York, NY: Oxford University Press; 2005:775–788.
- Saunders C. The challenge of terminal care. In: Symington T, Carter RL, eds. *Scientific Foundations of Oncology*. London, England: Heinemann; 1976:673–679.
- Krechel SW, Bildner J. CRIES: a new neonatal postoperative pain measurement score: initial testing of validity and reliability. *Paediatr Anaesth*. 1995;5(1):53–61.
- Manworren RC, Hynan LS. Clinical validation of FLACC: preverbal patient pain scale. *Pediatr Nurs*. 2003;29(2):140–146.
- Merkel SI, Voepel-Lewis T, Shayevitz JR, et al. The FLACC: a behavioral scale for scoring postoperative pain in young children. *Pediatr Nurs*. 1997;23(3):293–297.
- Bieri D, Reeve RA, Champion GD, et al. The Faces Pain Scale for the self-assessment of the severity of pain experienced by children: development, initial validation, and preliminary investigation for ratio scale properties. *Pain*. 1990;41(2):139–150.
- McGrath PA. Development of the World Health Organization Guidelines on Cancer Pain Relief and Palliative Care in Children. *J Pain Symptom Manage*. 1996;12(2):87–92.
- Belliemi C. Pain definitions revised: newborns not only feel pain, they also suffer. *Ethics Med*. 2005;21(1):5–9.
- Fitzgerald M AK. Developmental neuroanatomy and neurophysiology of pain. In: Schechter NL Berde CB, Yaster M, eds. *Pain in Infants, Children, and Adolescents*. Baltimore, MD: Williams and Wilkins; 1993:11–13.
- Pepino MY, Mennella JA. Sucrose-induced analgesia is related to sweet preferences in children but not adults. *Pain*. 2005;119(1–3):210–218.
- Anand KJS. Physiology of pain in infants and children. In: *Pain in Infancy and Childhood*. Annales Nestle; 1999: 57:1–12.
- Berde CB, Sethna NF. Analgesics for the treatment of pain in children. *N Engl J Med*. 2002;347(14):1094–1103.
- Indelicato RA, Portenoy RK. Opioid rotation in the management of refractory cancer pain. *J Clin Oncol*. 2003; 21 (9 Suppl.): 87s-91s.
- Friedrichsdorf SJ, Kang TI. The management of pain in children with life-limiting illnesses. *Pediatr Clin North Am*. 2007;54(5):645–672, x.

Sam: A Case Study

Learning objectives:

1. Review and discuss the pain assessment and management in children.
2. Discuss some of the unique factors complicating assessment and management in pediatric care.
3. Discuss goals of care, DNAR orders, and comfort measures in children.
4. Review the role of the specialist in pediatric care.

PATIENT PROFILE

Case

Sam is a 13-year-old with a history of osteosarcoma thought to be cured after a limb salvage procedure 1 year ago. He now is admitted to the hospital with a mass in his right flank and complaining of pain. The throbbing pain started in his side, has been worsening during the past 2 months, and, now, makes it difficult to sit and stand straight. He can only lie down on his right side.

His mother, who has made most of his medical decisions, is clearly very anxious. When asked why he let it go so long, he simply looks at his mother and says sadly, “I don’t know, sorry Mom.” When the resident starts to ask details about the pain, Sam’s mother gets very angry and simply says, “Can you please just go get Dr. Smith, Sam’s pediatric oncologist?”

FACILITATOR

What are the complicating factors in this assessment?

1. Emotional: Clearly, the mother and child are worried about what the mass in his side means. They are both anxious and, most likely, are not as worried about the pain as they are the recurrence of the cancer.

2. Social: Sam is a teenager, which adds a complexity to assessment (he may act autonomously but is not developmentally prepared to understand the implications of his decisions). Children of all ages may withhold information from their parents. Small children may think the pain is a sign they did something bad and not tell their parents for fear of getting in trouble. Older children, like Sam, may not tell because they do not want to burden their parents with the potential bad news or simply do not want to deal with the situation. In any case, the family dynamic and level of communication may add a layer of complexity to the assessment.

Case

The resident tells Sam’s mother, “I am sorry that Dr Smith is not here yet, but she will be here shortly.” She goes on to tell the mother that Dr Smith asked her to get a good assessment of everything that is going on with Sam so they can better understand what the next step is. She apologizes for the delay but asks if she can talk to Sam about his pain. The mother agrees. The resident then asks Sam, and he, too, agrees.

FACILITATOR

What did the resident do well?

The resident openly recognized the mother’s anxiety and answered her question without making her feel belittled. She then recognized the decision-making authority of the mother and—by asking permission from the parent *and* the child—was able to forge a relationship that allowed her to perform the rest of her assessment.

Case

Sam reports that there are two components to the pain, a constant 6/10 throbbing pain that is bearable and a 10/10 transient shooting/stabbing pain radiating down his leg that only occurs when he stands up from lying or sitting. It goes away after a couple of minutes but it is excruciating. The resident knows that Sam is being admitted for a workup of his flank mass, and he has no medical allergies.

FACILITATOR

What are the types of pain we are dealing with in Sam, and what would be a reasonable initial treatment?

NOTES

1. Musculoskeletal/somatic: Throbbing pain
2. Incident pain: Likely from muscle spasm, vertebral compression, or nerve impingement

Treatment of his pain during the evaluation period is appropriate. Initiating intravenous morphine would allow the team to assess his level of pain and make quick changes based on level of pain control. Because the cause of the incident pain is unclear, we are unsure of the proper treatment. The resident should evaluate with magnetic resonance imaging of the lumbar spine, abdomen, and pelvis.

Case

Scheduled intravenous morphine (0.2 mg/kg per dose every 4 hours) is started with an as-needed rescue dose (0.1 mg/kg per dose every 15 minutes as needed).

Magnetic resonance imaging shows a large mass in Sam's pelvis that is compressing his lumbar spine and sacral vertebra. After initiation of the scheduled morphine, Sam's nurses and mother note that he seldom gets out of bed and never really talks when the doctors are in the room. He does not, however, complain of pain. His mother pulls the resident aside and says she is very worried about him. Sam's oncologist, the physician who has known him the longest, agrees that this behavior is odd for Sam and asks a child life specialist and the psychologist that Sam has worked with in the past to get involved.

Sam reveals that he is feeling very sad and isolated from his friends and everything he likes to do. A plan is made with him to help feel more connected to his life outside the hospital. He then lets his mother and the resident know that his pain is down to a 3/10 or 4/10 right after the dose of morphine but is again a 7/10 to 8/10 within a couple of hours. Every time he moves, the pain shoots up to a 10/10 for about 15 or 20 minutes.

FACILITATOR

What did the resident do well?

The resident recognized that Sam was withdrawn and asked the people who knew him best to evaluate his behavior. Using clinicians who know Sam and the addition of a child life specialist and a psychologist are helpful for Sam in discussing things on his terms and can often lead to improvements in communication and assessment.

What is the next step in pain control?

The resident should convert to the use of patient-controlled analgesia (PCA) for Sam. Discuss proper PCA dosing, including conversion from scheduled dosing, proper bolus amounts to control breakthrough and incident pain, and frequent reevaluation to ensure proper control. Also discuss the role of treating incident pain and why transmucosal (easy to use in home setting) fentanyl (fast acting with short half-life) is a decent choice.

Case

Sam is doing better with the PCA (0.05 mg/kg/h basal with 0.025 mg/kg per dose bolus and lockout of 8 minutes). After a number of escalations in his dose, he is only needing rescue doses when he gets nursing assessments and sometimes in the night when he accidentally rolls over. Transmucosal fentanyl is started for Sam when he wants to get up to go to the bathroom or walk around the room.

Further evaluation shows that Sam has metastases throughout his abdomen and lungs. An aggressive chemotherapy plan is started, but a repeated computed tomography scan, after two weeks of treatment, shows that the metastases are actually growing.

In a family meeting with Sam's mother and father, Dr. Smith facilitates a discussion about the treatment failure. When asked what they would hope for at this point, the mother says, "Well, a cure, of course, but at least some more time." After a few minutes of quietly thinking, the parents decide they would like Sam "to stay around as long as possible, but only do invasive things if absolutely necessary." Dr. Smith asks the family members if they would like help talking to Sam, and the three of them and Sam's psychologist go in to talk with him.

FACILITATOR

Are these appropriate goals of care?

In general, the family should set the goals of care. Despite the spread of disease, Sam may have a few months or more to live.

Is it appropriate to not include Sam in the discussion/family meeting?

Sam is still a nonautonomous person. However, he is of a developmental stage in which he can understand and have opinions about his medical care. The decision to include a

NOTES

child in conversations should be based on the developmental stage of the child, the wishes of the patient and family, and whether the child has been involved in decision making in the past. The family meeting is appropriate, especially if Sam feels the next steps are appropriate. If he does not provide assent, then more discussions are warranted.

Case

Sam does well for a couple of months, with one admission for inadequate pain control. Then he is admitted for worsening shortness of breath. A chest radiograph reveals that he has bilateral, presumably malignant, pulmonary effusions.

Dr. Smith discusses potential medical interventions if Sam were to go into cardiopulmonary arrest. She says, “Given the progression of his cancer and the lack of effective treatment, I worry about putting him through a code. More important, though, I think a code would go against our hope to keep Sam comfortable.” At the end of the conversation, the family and Dr. Smith decide that it is best to include DNAR and DNI orders in Sam’s care plan. They then discuss treatment options for pain and dyspnea and decide to go home with hospice.

Sam meets his hospice agency at home. The hospice team aggressively manages his pain and dyspnea—requiring escalating doses of intravenous morphine and lorazepam. At his death, he is comfortable, and his family is at his bedside.

FACILITATOR

Wrap up case and open for discussion.

NOTES



CHAPTER 14

Cross-Cultural Encounters



Learning Objectives

Attitudes

- Develop appreciation for the prevalence of cross-cultural encounters and common barriers that arise.
- Value the importance of cultural competence in palliative care.
- Gain insight into one's own culture and values and how these affect beliefs about palliative care.

Knowledge

- Define culture and its impact on palliative care.
- Describe the explanatory model and its use in understanding cultural influences.
- Identify various death-related activities and how they may be affected by culture.
- Define ritual and explain its role in palliative care.

Skills

- Demonstrate the ability to respond appropriately to a request to withhold information from a patient.
- Demonstrate the ability to assess beliefs and practices about death and dying in a patient and family of a background different from one's own.
- Demonstrate the ability to enlist resources that will assist in understanding and working with people from different cultural backgrounds.

NOTES

Pre/Post Test

1. Define culture.

2. List two attributes that contribute to an individual's cultural identity.

a.

b.

3. Name two death-related rituals that vary across cultures.

a.

b.

4. Write two questions you might ask someone from a very different culture to help you understand how they view and understand an episode of illness.

a.

b.

Answers

(1) a set of guidelines that individual people acquire from their society, (2) gender, age, (3) burial practices, preparation of the body, (4) What do you call the problem? Why do you believe the problem occurred?

Most things that don't make sense from the outside usually do make sense if understood from the inside....

Cross-cultural encounters are inevitable in surgical practice, especially for surgeons working in large urban areas, the military, or in foreign countries. Cultural differences become even more significant factors in influencing outcome when the occasion is one of heightened social and spiritual significance (birth, grave illness, death). Cross-cultural medical encounters can go very well or very poorly, depending on the surgeon's knowledge, attitudes, and skills when working with people from different cultural backgrounds. The goal of this chapter is to give surgeons key concepts, tools, and clinical communication skills to better illuminate the common ground shared by culturally diverse participants caring for patients at the end of life. The chapter does not assume that the surgeon be versed in the history, beliefs, and practices of the world's hundreds of cultures, but it does assume respectful cross-cultural contact is necessary for optimal patient care. *Cultural competency is not the same as cultural literacy. Cultural competence is the ability to interact with people of different cultures. Cultural literacy is knowledge of other cultures.*

What Is Culture?

Culture is more than just ethnicity, skin color, or religion. A variety of other attributes contribute to our cultural makeup, including national and geographic origin, current home, gender, sexual orientation, age and generation, marital status, family, and professional and community roles. It is important for all clinicians to remember that we, too, have our own cultures, including the culture of surgery. Our cultural makeup significantly influences our interactions with patients and families and the care we provide. We can better serve the people we work with by gaining insight into our own cultural makeup.

Definitions of Culture

"A set of guidelines (both explicit and implicit) which individuals inherit as members of a particular society, and which tells them how to view the world, how to experience it emotionally, and how to *behave* in it in relation to other people, to supernatural forces or gods, and to the natural environment." (Helman CG. *Culture Health and Illness*. 3rd ed. London, England: Butterworth Heinemann; 1994:2.)

"Culture is the shared knowledge and schemes created by a set of people for perceiving, interpreting, expressing, and responding to the social realities around them." (Ledarch JP. *Preparing for Peace: Conflict Transformation Across Cultures*. Syracuse, NY: Syracuse University Press; 1995:9.)

NOTES

Challenges in Working Across Cultures

- **Language**

Avoid using family members as translators because they may filter communication. Use professional translators whenever possible. Also note that interpreters of a different sex or social class from that of the patient can alter the dynamics of the interaction.

- **Misunderstandings**

Misunderstandings occur when something is said or done with one intent or meaning and it is interpreted to have a different intent or meaning. This situation is particularly a problem in end-of-life care because many cultures rely on indirect, symbolic communication about illness and dying.

- **Differing values and meanings**

Values and the meaning invested in certain behaviors or rituals may vary dramatically across cultures and even within cultures. It is difficult to avoid extremes of cultural stereotyping on the one hand and ignoring real differences, where they exist, on the other hand.

- **Imposed relationships**

As people approach the end of life, regardless of socioeconomic class, they are more likely to become dependent on others from very different cultural backgrounds. There is little if any choice; these relationships are *imposed*. The nature of such imposed relationships makes misunderstandings more common and conflict, based on misunderstandings and differing values, more likely.

- **History and prejudice**

People carry with them their history. Sadly, the historic relationship between members of many groups is characterized by distrust, prejudice, and even hatred. Clinicians may like to think that they are immune to the effects of such distrust or prejudice—in their patients or themselves—because we as clinicians imagine ourselves to have only beneficent intents. It is difficult to acknowledge that history and prejudice may themselves pose a significant challenge for our patients and for us.

- **The power of ritual**

Ritual is a process of making *human* that which is *biologic*. Ritual can be defined as repetitive behavior for a nontechnical purpose that is imbued with meaning. Ritual is particularly important in life transitions, such as birth, puberty, and dying. Clinicians tend to underestimate the power and importance of ritual. If dying is reduced to a biologic or medical event, ritual for patients, families, and clinicians will be devalued. It is also natural for people to have little insight into their own rituals; most people when asked why they do something a certain way will say, “because that’s how it is done.” Clinicians cloaked in science have trouble recognizing the importance of rituals in others but may have even greater difficulty recognizing the ritual behavior in which they themselves are engaged.

NOTES

The Explanatory Model

This *Guide* uses a model of culture known as “The Explanatory Model,” developed by Arthur Kleinman, a physician and anthropologist, specifically for patient-physician encounters. Explanations of how one became ill, what the consequences of the illness are (indeed, what the illness is), and the roles of various parties in relating to the ill patient vary dramatically across cultures. Getting to the patient’s and the family’s explanatory model (and developing insight into one’s *own* model) can go a long way toward promoting understanding. Such understanding is often critical when dealing with people from very different backgrounds and when encountering a serious disagreement in which the “other side’s” position makes no sense. Remember: *Most things that don’t make sense from the outside usually do make sense if understood from the inside...*

QUESTIONS TO ASK TO EXPLORE THE EXPLANATORY MODEL

What...

- Do you call the problem?
- Do you think the sickness does?
- Do you think is the natural course of the illness?
- Is it you fear?

Why...

- Do you believe this problem occurred?

How...

- Do you think the sickness should be treated?

Who...

- Should one turn to for help?
- Should be involved in care and decision making?

Exploration of Dying and Death-Related Beliefs and Practices

Exploration of end-of-life, dying-, and death-related practices is particularly important when encountering a patient or family from a group with which the practitioner is unfamiliar. In many communities, the norm is *not* to discuss death, especially a specific person’s death. At best, it is simply considered bizarre or impolite to talk about death. Also, in many communities throughout the world, communal decision making is common. Occasionally, a community leader may be the appropriate decision maker regarding a sick person. But often, the physician is thought to be the appropriate decision maker, and so, when the physician requests that someone else make decisions, it is experienced as confusing and, at times, distressing.

Trust and Mistrust: Culturally Contextualizing the Physician-Patient Relationship

When mistrust of the medical profession is present, the meaning of end-of-life discussion and requests for decision making become charged in ways that an aware surgeon can anticipate, address, and often ameliorate. While sometimes mistrust should be anticipated, or at least recognized and understood, it should be noted that in the United States, there is less respect or deference to physician authority than in many cultures abroad. Many cultures do not share the prevailing US belief that individuals should control their own health care. People with such cultural backgrounds may find it confusing or even distressing when a contemporary US physician seeks collaboration with a coequal patient in the spirit of patient autonomy.

NOTES

Understanding and Respecting a Multiplicity of Practices at the End of Life

Wise surgeons anticipate that almost all patients are engaging in a wide range of health behaviors. If a surgeon wants an honest accounting from patients about their health-related choices, a useful practical approach is to use the Explanatory Model questions and strive to be nonjudgmental and open. This approach means support for the patient's and family's choices of alternative modalities of treatment in the pursuit of "what is right for them" as long as the choices are not illegal, dangerous, or disrespectful to others. At the end of life, it is particularly important to support the patients' right to use diverse forms of treatment in recognition that dying is a deeply personal process and not a medical problem to be solved. Many hospitals or nursing facilities can accommodate such choices, better so with the attending surgeon's support.

The Symbolic Meanings of DNR and Hospice

End-of-life conversations and decision making about hospice and DNR orders mean something quite different to patients and families from what these activities mean to physicians and nurses. Patients and families, whatever their cultural community or background, often perceive end-of-life decision making as a demand that they choose life or choose death. Ethnographic research clearly indicates that patients and families experience choosing a DNR order or choosing hospice as "choosing death over life." In this respect, any time that a patient is not a participant in the culture of medicine, in other words, *most of the time*, the end of life is a cross-cultural encounter.

Goals of Care

The concept of goals of care reframes the choice to be made. One is no longer choosing between life and death. Instead, the choice is which of three goals of care are most in line with the patient's lifelong personality and values.

The concept of goals of care recognizes three common goals of care sought by surgeons:

- Comfort
- Function
- Longevity

Whenever possible in medicine, we seek to achieve all three of these goals of care, and, often, we are able to do so. However, sometimes, to achieve the goal of longevity—to lengthen the patient's life by as many days or weeks as possible—we must sacrifice comfort and pursue painful treatments that cause suffering. Many patients may want to trade off or sacrifice comfort to pursue longevity if the achievable goal is years or months; some may want to make the trade for every day of life possible. Yet others will say that they want to pursue the goal of comfort, even if it means that they trade off longevity and live a shorter time but with palliation of burdensome symptoms. For still others, the goal of function, being able to do activities of paramount personal importance, trumps goals of comfort and longevity, and they can clearly articulate that they would not want to be kept alive longer if they had to trade off function "X" to do so.

By discussing these three goals of care with patients and their families, the focus of the conversation shifts to how they would like to live, rather than if they would like to live or even how they would like to die.

A surgeon can establish a safe space for articulating preferences by enumerating a variety of multiple-choice options in which it is clearly stated that "Some patients and families believe that 'A' is right for them, some believe that 'B' is more right for them, and others believe that 'C' is most appropriate for them. There is no right answer. My goal is to better understand you and your family and to come to understand what is the best thing for you..."

NOTES

BELIEFS AND PRACTICES THAT MAY BE EXPLORED

- How are people informed about or how do they communicate about a serious or terminal illness? (direct, indirect)
- Preparation and approach to dying (fighting, fatalistic, accepting)
- Symptom and medical management (stoic or vocal approaches to distress, self-care practices and home remedies, complementary therapies)
- Approaches to feeding and nutrition of dying patients
- Desired location of dying (home, hospital)
- Spiritual, religious needs, rituals
- Before death, at time of death, and following death
- Care of the body following death (washing, placement of body [directional, Islam], speed in moving the body [Buddhist, slow; Jewish, fast], desired clothing)
- Grief practices (restrained, demonstrative, ritual behavior, and anniversaries)
- Attitudes toward organ donation, autopsy (accepting, nonaccepting)
- Funeral practices

NOTE: Especially when asking questions about death, it may be wise to initially *detoxify* questions, by stating that you are *not* inquiring about the patient but about general cultural practices because many cultures have taboos against speaking explicitly about the dying of a sick patient; it is believed this practice may hasten death. If the person with whom you are speaking continues to speak indirectly (“In our culture, this is how things are done...”), continue *not* speaking directly about the dying person. If the person begins to talk more openly (“When he dies, this is what we want.”), you have probably been given permission to address more directly what will happen within that family.

IN EXPLORING BELIEFS AND PRACTICES, YOU MAY CONSIDER THE FOLLOWING GENERAL APPROACH AND TYPES OF QUESTIONS:

- Statement of respect, desire to learn
EXAMPLE: “I know very little about how people from East India respond to things at such a time. I understand and respect the fact that different people handle things in very different ways. I would very much appreciate it if you would teach me what I need to know to be of help.”
- What is important
For the dying person to do?
For caregivers and families to do?
For the dying person?
At the time of death?
Following death?
- Are there important things that we should not do
At the time of death?
Following death?
- Do you have any special concerns or fears that we should know about?
- How could we be most helpful to the patient and family
In the dying process?
At the moment of death?
Following death?
- Reaffirm intent to help. Give permission to let us know if we make a mistake.

NOTES

Dealing with a Request for Nondisclosure

KEY POINTS

- A request for nondisclosure (don't tell grandmother she's dying) is often rooted in cultural beliefs and practices of the family. Such beliefs and practices are common.
- A belief system wherein the dying person is not told and others make health care decisions is not necessarily wrong. The prevailing belief system in Western health care that the "patient has a right to know" is not an absolute.
- Skilled communication and negotiation are required to intervene between people who desire nondisclosure and a health care system that is overtly based on disclosure and the patient's right to know.

SUGGESTED STEPS FOR EXPLORING A REQUEST FOR NONDISCLOSURE

• Statement of respect

EXAMPLES: *"I respect that different people have different opinions and beliefs about how such things are handled. Thank you for letting me know of your concern."*

• Why has this request been made?

EXAMPLE: *"Is there some particular reason you would prefer to handle things this way, or do you have a special concern about what might happen if I talked directly with her?"*

• Where do they think the patient would stand on this issue?

EXAMPLE: *"Do you think or know that grandmother would agree with this? Have you discussed this approach with her? How has she dealt with similar situations (prior deaths if any) in the past?"*

- **Statement of own values:** This statement should be made in a noncoercive manner, simply as a matter of explanation, explaining common practice and personal values.

EXAMPLE: *"In the United States, most people believe that clear-thinking patients should make their own decisions." "It is important to me to tell the truth, when speaking with people."*

• Propose a negotiated approach.

EXAMPLE: *"I've heard what you've said and respect where you are coming from. What I would like to do is to simply confirm with your grandmother that she is okay with leaving the details to you."*

- **Set ground rules for discussion.** Most physicians, I think, would like it clearly understood that if the patient says, "No, I want to be in charge. Tell me the whole truth." that it violates the physician's ethics to lie.

EXAMPLE: *"Assuming your grandmother agrees, I'm fine not talking with her about details of her disease and having you make decisions. However, if she asks me to tell the truth or that she wants to be in charge, I cannot lie. Do you understand and agree to this?"*

• Talk with the patient.

EXAMPLE: *"I understand in your family that the details regarding your medical condition and care are usually discussed and decided on by the family (or a specific member). Is this the way you would like me to handle things?"*

If yes, then there is no problem. *To defer one's autonomy is itself an act of autonomy.*

If no, then it is suggested that this response be discussed with the family members before proceeding to further discussion with the patient.

NOTES

Resources

Resources in your health care setting can include translators and/or *cultural guides*, people who can assist you in understanding patients and families from different backgrounds. Other local resources include health care workers from a similar background in your institution, who can help facilitate understanding between the “system” and the patient or family. Local community and religious groups may also be great resources in providing guidance and support to the patient and family.

BOOKS

- Braun KL. *Cultural Issues in End-of-Life Care*. Sage Publications; 2000. This book provides a good overview and addresses specific issues in specific subpopulations, such as African Americans, Hispanics, disability groups, and patients with AIDS.
- Crawley LM, Marshall PA, Lo B, et al. Strategies for culturally effective end-of-life care. *Ann Intern Med*. 2002;136:673–679.
- Fadiman A. *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*. New York, NY: Farrar, Strauss, and Giroux Publishers; 1998. A superb description of a Hmong girl with a seizure disorder and the cultural conflicts that arose between Western medical practitioners and the Hmong people in trying to care for her.
- Helman CG. *Culture Health and Illness*. 3rd ed. London, England: Butterworth Heinemann; 1994. A superb introduction to medical anthropology, not specific to end-of-life care.
- Irish D, Lundquist K. *Ethnic Variations in Dying, Death and Grief*. Washington, DC: Taylor and Francis; 1993. A more focused book on death-related practices of major ethnic groups in the United States. However, this does not have the breadth of the book by Lipson et al.
- Lipson JG, Dibble SL, Minarik PA. *Culture & Nursing Care: A Pocket Guide*. San Francisco, CA: UCSF Nursing Press; 1996. Perhaps best pocket reference. Has detailed descriptions of death-related practices for 23 ethnic groups.

ARTICLES

- Barclay JS, Blackhall LJ, Tulskey JA. Communication strategies and cultural issues in the delivery of bad news. *J Palliat Med*. 2007;10:957–977.
- Blackhall LJ, Murphy ST, Frank G, et al. Ethnicity and attitudes toward patient autonomy. *JAMA*. 1995;274:820–825. Useful in considering issues, such as disclosure.
- Dula A. The life and death of Miss Mildred. *Clin Ethics*. 1994;10(3):419–430. Useful in teaching because it illustrates cultural differences between a poor, elderly African American woman and the health care system with which she interacts. Skillfully allows the reader access to the perspective of the patient and how she views her situation and the health care system.
- Hallenbeck JL, Goldstein MK, Mebane EW. Cultural considerations of death and dying in the United States. *Clin Geriatr*. 1996;12(2):393–406. Identifies different types of cultural misunderstandings that can arise in end-of-life care.
- Hallenbeck JL, Goldstein, MK. Decisions at the end of life: cultural considerations beyond medical ethics. *Generations*. 1999;23(1):24–29. Considers the cultural relativity of Western medical ethics and problems that arise when different value systems are not understood in addressing common ethical problems at the end of life.
- Kleinman A. Culture, illness and cure: clinical lessons from anthropologic and cross-cultural research. *Ann Intern Med*. 1978;88:251–258. From the creator of the “explanatory model”: a classic article introducing this concept to the medical community.
- Loudon RF, Anderson PM, Singh Gill P, et al. Educating medical students for work in culturally diverse societies. *JAMA*. 1999;282(9):875–880. Excellent systematic review; covers other article that have examined this issue.
- Orona CJ, Koenig BA, Davis AJ. Cultural aspects of non-disclosure. *Cambridge Q Healthc Ethics*. 1994;3:338–346.

WEB SITES

<http://www.xculture.org/> Focuses on cross-cultural health care; vast resources and links available; excellent start-site for Web searches on the topic.

<http://www.ama-assn.org/ethic/diversity/contents.htm> Acrobat file of 460-page American Medical Association report entitled “Cultural Competence Compendium.” Excellent reference work with reviews of major articles and resources in the field. Also can be purchased from the American Medical Association. For purchase, see information on the Web site.

Culture and End-of-Life Care Role-Playing Exercises | Faculty Guide

Five exercises are included to explore different aspects of culture and end-of-life care.

1. Explanatory Model: Role-playing exercise
2. Explanatory Model: Personal exploration exercise
3. Exploring death-related practices: Role-playing exercise
4. Exploring a request for nondisclosure exercise (“Don’t tell grandmother”): Role-playing exercise
5. Finding cultural resources exercise

1. Explanatory Model: Role-playing exercise

Purposes

To practice the skill of eliciting an explanatory model and to gain insight into one’s own explanatory model of illness. The learner will practice asking *what*, *why*, *how*, and *who* questions.

Method

One learner takes the part of the clinician and one the part of a person from a different culture (patient or family member). While the learner playing the family or patient role may play himself or herself, it is helpful if the explanatory model is significantly different from the Western medical model to highlight differences. Faculty and learners may decide before the role play what particular illness is to be explained. The illness may or may not be terminal. The script that follows is for a patient from a non-Western culture with a brain tumor who is experiencing seizures. **Note:** After the role play, highlight differences between answers from a Western clinician and a person from the culture of the patient with a brain tumor.

Clinician Role: You have just admitted a patient with a glioblastoma multiforme who has begun having recurrent seizures. The family appears distressed by the seizures, but also looked unhappy when the patient was given intravenous and oral medications. The nursing staff describes the family as uncooperative and the patient as noncompliant with medications. On entering the room, you notice a strange, herbal odor. The patient’s gown is open at the front, and a greasy, foul-smelling ointment has been applied to the chest. You ask to speak to the patient to try and elucidate the explanatory model for this illness.

Patient Role: You are a recent immigrant to the United States. A few months ago, you began having pains in your head and feeling strangely. Two weeks ago, you were admitted when you had a spell. After you woke up, the doctors told you they had to drill a hole in your head. You were scared but hoped that by drilling the hole, whatever spirit was trapped in your head would be released. After that, they told you that you had something bad in your head. Releasing the bad spirit didn’t work; it was too big. Recently, the spirit has been possessing you more frequently. You are afraid that the spirit might take your soul away. If that happened, you would not only die, but also be unable to find your way to the afterworld. The Western medicine you have been given hasn’t helped, so you are reluctant to keep taking it. Your family contacted a medicine man, who told them to apply a special herbal lotion to your chest, which will irritate the spirit and make it leave.

NOTES

2. Explanatory Model: Personal exploration exercise

(This exercise can be performed more rapidly than the role-playing exercise in Number 1. It is especially good for self-reflection on how the medical model is itself an explanatory model but does not allow skill practice.)

Purpose

To understand how different cultures have different ways of explaining medical phenomena.

Method

Distribute the worksheet (following page), ask the group to explain *their* explanatory model for seizures, asking the group, *what, why, how, and who* questions (for example, “*What is a seizure?*” An electrical discharge in the brain...). After this, read the excerpt from, *The Spirit Catches You and You Fall Down*. This book is about a young Hmong girl with seizures. The Hmong are a mountain people from Laos who settled in large numbers in the area of Fresno, CA, and other areas. Note how different the explanatory models are and the potential for misunderstandings and confusion.

FROM *THE SPIRIT CATCHES YOU AND YOU FALL DOWN*¹:

1. What do you call the problem?
Qaug dab peg. That means the spirit catches you and you fall down.
2. What do you think has caused the problem?
Soul loss.
3. Why do you think it started when it did?
Lia’s sister, Yer, slammed the door and Lia’s soul was frightened out of her body.
4. What do you think the sickness does? How does it work?
It makes Lia shake and fall down. It works because a spirit called a *dab* is catching her.

5. How severe is the sickness? Will it have a short or long course?
Why are you asking us those questions? If you are a good doctor, you should know the answers yourself.
6. What kind of treatment do you think the patient should receive? What are the most important results you hope she receives from this treatment?
You should give Lia medicine to take for a week but no longer. After she is well, she should stop taking the medicine. You should not treat her by taking her blood or the fluid from her backbone. Lia should also be treated at home with our Hmong medicines and by sacrificing pigs and chickens. We hope Lia will be healthy, but we are not sure we want her to stop shaking forever because it makes her noble in our culture, and when she grows she might become a shaman.
7. What are the chief problems the sickness has caused?
It has made us sad to see Lia hurt, and it has made us angry at Yer.
8. What do you fear most about the sickness?
That Lia’s soul will never return.

¹From: Fadiman A. *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*. New York, NY: Farrar, Strauss, and Giroux Publishers; 1998:260–261.

NOTES

Worksheet—Explanatory Model Exploration

Write your answers below.

How do you explain the phenomenon of seizures? What is a seizure?

Why does a seizure occur?

How does a seizure occur?

Who experiences seizures?

NOTES

3. Exploring Death-Related Practices: Role-playing exercise

Purpose

To practice the skill of learning about another cultures' death-related practices.

Method

One person will be the surgeon, the other the relative of a dying patient of a cultural background with which the surgeon is unfamiliar. Before the role play, clarify the relationship of the relative to the patient and give a very rough sketch of the cultural background of the family being represented (perhaps race, national origin, and/or religious background). The person playing the relative may choose to act the part of someone from his or her own background or may alter the background as desired. Encourage learners playing the part of the family member to answer as if his or her own family were involved, if comfortable doing so, because this approach promotes self-reflection.

Scenario: The scene is a peaceful one. There is no immediate medical crisis. It appears that the relative is well aware that the patient is dying.

Surgeon Role: You have just admitted a patient from a background very different from your own. You are unsure how to approach the patient or the family and to be of help relative to patient's impending death, which may happen in a matter of days. You ask to speak to a relative to get some understanding of dying- and death-related practices so that you can understand their needs.

Relative Role: Your relative (fill in the blank with relation to you) has been admitted to the hospital and is obviously dying. The doctor asks to speak with you for a few moments.

4. Exploring a Request for Nondisclosure Exercise (“Don’t tell grandmother”): Role-playing exercise

Purpose

Practice the skill of dealing with a request for nondisclosure.

Method

One person will be the surgeon, the other the relative of a dying patient of a cultural background different from that of the physician. The person playing the relative may choose to act the part of someone from his or her own background or may alter the background, as desired. Encourage learners playing the part of the family member to answer as if his or her own family were involved, if comfortable doing so because this approach promotes self-reflection.

Surgeon Role: You are meeting with the son (or daughter) of a patient, who is dying. He (or she) has requested to talk with you. You are considering a hospice referral. Usually, you would discuss hospice as an option with the patient. However, you are stopped in the hall and told that the family does not want you to tell the mother that she is dying. You meet to discuss this.

Son or Daughter of Patient Role: You are meeting with your mother's physician. You know your mother is dying but believe it would destroy her hope if she knew. You think she might in fact know it already, but it would not be proper to speak of such things. You have never discussed directly your mother's wishes, but you believe this is consistent with your cultural and family values. At a certain age, the oldest child becomes the family spokesperson and makes decisions. It is not proper to speak of death with the dying person. When your father died seven years ago of cancer, your mother also believed it was best not to tell him.

NOTES

Pre/Post Test

1. What are four important definitions or features of culture?
 - a. Shared set of traits, beliefs, and behaviors
 - b. Grammar for living
 - c. Meaning as central to culture
 - d. Culture is a dynamic process, never static
2. What are three key cultural themes that arise at the end of life and are important to keep in mind in all cross-cultural encounters?
 - a. Trust or mistrust in physician-patient relationship
 - b. Norms of communication, especially about death
 - c. Decision making
3. What is meant by goals of care, and how is this a useful concept in managing cross-cultural encounters at the end of life?
 - a. Description of the three goal of care: comfort, function, and longevity
 - b. Reframing choice to “How do you want to live?” Not “How do you want to die?” Or “Do you want to live?”
 - c. Key phrases that give permission for any of the goals of care to be the priority for the patient and family
4. How would you manage a request to “not tell” the patient the diagnosis?
 - a. Key phrases that invite the patient and family to guide the physician regarding how much information they want to know and with whom they want the physician to speak..
5. How would you seek additional resources and assistance in working with a patient and family of a cultural community quite distinct from your own? (Discuss at least five things.)

NOTES

CHAPTER 15

Delivering Bad News



Learning Objectives

Attitudes

- Reflect on prior good and bad experiences delivering bad news.
- Value the physician's role in delivering bad news in a compassionate, honest, and direct manner.
- Respect the patient's autonomy and right to understand the nature of his or her medical status.

Knowledge

- Understand the physical setting where a discussion of bad news should be conducted.
- Understand who should be involved in a discussion of bad news.
- Demonstrate knowledge of the first key steps for delivering bad news.
- Demonstrate knowledge of key steps in delivering bad news by telephone.
- Describe key steps in how to follow-up after a discussion of bad news.

Skills

- Demonstrate how to open a discussion when bad news will be presented.
- Demonstrate the ability to deliver bad news with honesty and compassion.
- Demonstrate ability to assess patient and family understanding and respond to their needs.
- Demonstrate ability to respond appropriately to strong patient emotions (such as sadness, fear, anger).
- Demonstrate how to conclude a discussion of bad news.

NOTES

Pre/Post Test

1. Describe the first three steps in breaking bad news.

- a. _____
- b. _____
- c. _____

2. Describe the words to use when giving a “warning shot” before giving bad news.

“ _____ ”

3. Before giving bad news over the telephone, what two issues must be clarified between yourself and the person with whom you are speaking?

- a. _____
- b. _____

4. Describe four common patient reactions to receiving bad news.

- a. _____
- b. _____
- c. _____
- d. _____

Answers

(1) Determine what the patient knows, give a warning shot, give the bad news. (2) I'm afraid I have some bad news. (3) Each person needs to explain his or her relationship to the patient (doctor and other person). (4) anger, guilt, grief, denial

Teaching Outline

Delivering bad news is an invasive procedure that requires all of the thoughtfulness and skill required to perform a safe and competent operative procedure. The delivery of bad news and surgery both require an appropriate setting, assistance when indicated, patient permission, skillful execution, ongoing assessment of the impact of the intervention on the recipient, and aftercare.

Create an Appropriate Context

1. Physical setting: Choose a quiet, comfortable room; turn off pager and other personal electronic devices; check personal appearance; have participants, including yourself, sitting down.
2. Know the basic information about the patient's disease, prognosis, and treatment options.
3. Who should be present?
 - Ask the patient whom they want to participate; clarify relationships to patient. Make sure legal decision maker is present.
 - Decide if you want others present (for example, nurse, consultant, chaplain, social worker) and obtain patient and/or family permission. **NOTE:** For life-threatening bad news, it is recommended that you have a nurse, social worker, or chaplain present to assist you and provide additional emotional support to the patient and family.
 - Security may also be appropriate, depending on the size of the group, when delivering life-threatening bad news after a violent event.
4. Obtain a skilled medical interpreter if the patient or family members do not speak English or have hearing impairments.
5. Think through your goals for the meeting and possible goals of the patient.

First Steps

1. Determine if the patient and family can understand information: Are there medical, cognitive, or psychological reasons for diminished understanding (such as pain, mental retardation, delirium, dementia, emotional upset).
2. Learn what the patient and family already knows; make no assumptions. For example, ask "What is your understanding of your present condition?" or "What have the doctors told you about your condition?" Shape your discussion to the patient's and family's needs.
3. Before presenting bad news, it is sometimes appropriate to provide a concise two to four sentences) narrative overview of the patient's hospitalization, diagnostic procedures, and medical status so that every one has a common source of information; avoid use of jargon.

NOTES

Breaking Bad News

1. **Speak slowly, deliberately, and clearly.** Provide information in small chunks. Check reception of news frequently; closely observe patient body language.
2. **Give fair warning.** “I am afraid I have some bad news for you”; then pause for a moment.
3. **Present the bad news in a succinct manner.** Be prepared to repeat information and present additional information in response to patient and family needs.
4. **Sit quietly and listen to the patient.** Allow the patient time to absorb the news. You may wait for the patient to respond, or you may offer support (for example, “I’m so sorry”), but avoid the common mistake of rushing forward and talking because you are anxious.
5. **Anticipate common reactions to bad news:**
 - Overwhelming emotion: anger, fear, sadness, crying, isolation, guilt, relief, helplessness, anxiety
 - Numbness, often manifesting as an absence of emotion
 - Denial
 - Collusion: a request to withhold information from patient or family members
6. **Listen carefully and actively. Pick up clues. Recognize, acknowledge, and validate the patient’s and family’s emotions, reactions, and thoughts.** “This is very difficult news.” “This must be very hard.”
7. **Give an early opportunity for questions and comments.**
8. **Present information at the patient’s and family’s pace.** Do not overwhelm with detailed information. The discussion is like peeling an onion. Provide an initial overview, then assess understanding and answer questions. Then provide the next level of detail, assess understanding, and answer questions. Provide additional detail, or move back to the overview in response to the patient’s and family’s needs.
9. **Be flexible and responsive.** Allow the patient’s and family’s concerns and needs to mold the discussion.
10. **Be mindful** of your own feelings, thoughts, and reactions. Do not allow your reactions to derail you, offer false reassurance, overtalk, or commit other communication errors.
11. **Ask** “How can I help?”
12. **Assess thoughts of self-harm.** Based on how the patient and family members react, ask questions to assess risk of self-harm and suicide.
13. **Agree on a follow-up plan** (for example, “I will return later today; write down any questions you have.”) and make sure this meets the patient’s needs. Involve other team members in the follow-up plan.

NOTES

Document the Conference in the Chart

Who was present? What information was discussed? What actions need to be taken now? What follow-up is planned?

Assess Your Own Feelings and Needs

1. Guilt (“This is my fault. I missed his early symptoms. I’m supposed to help, not make things worse.”)
2. Anger (“I wouldn’t be in this situation if she had come for regular checkups....”)
3. Fear (“They are going to blame me for this. This same thing could happen to me.”)
4. Sadness (“How can this happen to this person?”)

Giving Bad News by Telephone

1. Avoid when possible; consider home or office visit. If you expect an important test result, schedule an office visit in advance to review results.
2. Make sure you have time to talk.
3. Clarify with whom you are speaking and the person’s relationship to the patient.
4. Introduce yourself and your role in the patient’s care.
5. Verify that the person can talk now.
6. Give fair warning: “I am afraid I have some bad news.”
7. In some cases, you may want to offer to meet with the person at the hospital or your office to present and discuss the bad news.
8. Offer to contact others, such as family members, clergy, or neighbors.

NOTES

Bibliography

- Ambuel B, Mazzone MF. Breaking bad news and discussing death. *Prim Care*. 2001;28(2):249–267.
- Amiel GE, Ungar L, Alperin M. Using an OSCE to assess primary care physicians' competence in breaking bad news. *Acad Med*. 2000;75(5):560–561.
- Baile WF, Buckman R, Schapira L, et al. Breaking bad news: more than just guidelines [letter]. *J Clin Oncol*. 2006;24:3217–3218.
- Buckman R. *How to Break Bad News: A Guide for Health Care Professionals*. Baltimore, MD: Johns Hopkins University Press; 1992.
- Creagan ET. How to break bad news—and not devastate the patient. *Mayo Clin Proc*. 1994;69:1015–1017.
- Eggly S, Afonso N, Rojas G, et al. An assessment of residents' competence in the delivery of bad news to patients. *Acad Med*. 1997;72(5):397–399.
- Eggly S, Penner L, Albrecht TL, et al. Discussing bad news in the outpatient oncology clinic: rethinking current communication guidelines. *J Clin Oncol*. 2006;24:716–719.
- Fallowfield L. Giving sad and bad news. *Lancet*. 1993;341:476.
- Fischere GS, Arnold RM. Feasibility of a brief workshop on palliative care communication skills for medical interns. *J Palliat Med*. 2007;10(1):19–23.
- Gordon GH. Giving bad news. In: Feldman MD, Christensen JF. *Behavioral Medicine in Primary Care: A Practical Approach*. Stamford, CT: Appleton & Lange; 1997:15–19.
- Iverson VK. *Pocket Protocols: Notifying Survivors About Sudden, Unexpected Deaths*. Tucson, AZ: Galen Press, Inc; 1999.
- Iverson VK. *Grave Words: Notifying Survivors About Sudden, Unexpected Deaths*. Tucson, AZ: Galen Press, Inc; 1999.
- Miller SJ, Hope T, Talbot DC. The development of a structured rating schedule (the BAS) to assess skills in breaking bad news. *Br J Cancer*. 1999;80(5–6):792–800.
- Pracek JT, Eberhardt TL. Breaking bad news: a review of the literature. *JAMA*. 1996;276:496–502.
- Silverman J, Kurtz S, Draper J. *Skills for Communicating with Patients*. 2nd ed. San Francisco, CA: Radcliffe Publishing; 2005.
- Quill TE, Townsend P. Bad news: delivery, dialogue and dilemmas. *Arch Intern Med*. 1991;151:463–468.
- Thomsen OO, Wulff HR, Martin A, et al. What do gastroenterologists in Europe tell cancer patients? *Lancet*. 1993;341:473–476.

Teaching Workshop and Role-Playing Exercise | Faculty Guide

1. Ask students to generate one or several case examples of real clinical situations in which they had to break bad news to a patient.
2. Review and discuss the **Breaking Bad News** teaching outline using the cases for illustration.
3. Ask students to form pairs or triads (patient/physician/observer).
4. Select one of the two role-playing exercises (see "Role-Playing Cases").
 - Students should spend five to seven minutes role playing.
 - i. Encourage students who role-play the family member or patient to adopt one of the various potential emotional reactions to receiving bad news:
 - ii. angry, hysterical, or showing profound sadness or disbelief
 - iii. Following the role-playing session, have the "patient" or "family member" complete the evaluation form and discuss it with their "physician" partner.
5. Depending on time, students can reverse roles and/or use the second case.
6. Debrief the student experience: What worked well, what did not, what was hard, what was easy?
7. Faculty may want to demonstrate their own technique at delivering bad news at the start or conclusion of the student role playing.

Role-Playing Cases

CASE 1: Death in emergency department (motor vehicle crash) in a previously healthy person

CASE 2: New diagnosis of metastatic stomach cancer

NOTES

Role-Playing Case 1

Purpose of Case: Giving bad news

Training Level: Medical students, postgraduate trainees, or faculty

Simulated patient name: Mr./Mrs. Jones

Event: Motor vehicle collision

Setting: Quiet room for family meetings in an emergency department

Time allotted: Seven minutes

Family Member Profile

MEDICAL HISTORY

Your spouse, Mr./Mrs. Jones, is a 54-year-old high school teacher with no history of any medical problems. He/she was involved in a motor vehicle collision on the way to work this morning, and you received a call from the hospital social worker that your spouse had been involved in a crash. You have been waiting in the waiting room, and you have not met the physician. You saw a nurse who said, “Your spouse is having some problems; the doctor will be out to talk with you soon.”

SOCIAL HISTORY

You have three children, ages 25, 22, and 17 years. Your parents are deceased; you have no siblings. You work as a new car salesperson.

SETTING

You are alone, in a quiet waiting room, located in the emergency department, sitting on a chair.

TASK

Your partner, in the role of the emergency department physician, will break the bad news to you. Some questions and comments you may want to pose (or any you think are appropriate to the situation) include the following:

- How can this be? He/she was fine this morning. We were planning to go on vacation next week!
- He’s/she’s never been sick a day in his/her life!
- What should I tell the children?

Information for Physician

MEDICAL HISTORY

You are on duty one early morning when a 54-year-old is brought in after a motor vehicle collision. The patient’s pulse was lost on arrival to the emergency department. You confirm that no vital signs are present, and you pronounce the patient dead. The nurse tells you that the spouse is in the waiting room and does not know about the cardiac arrest.

SETTING

The patient’s spouse is sitting alone in a waiting room in the emergency department, sitting in a chair.

TASK

You are the emergency department physician; tell the husband/wife that his/her spouse has died.

NOTES

Role-Playing Case 2

Purpose of Case: Giving bad news

Training level: Medical students, postgraduate trainees, or faculty

Simulated patient name: Mr./Mrs. Phillips

Diagnosis: Metastatic stomach cancer

Setting: Outpatient clinic office

Time allotted: Seven minutes

Patient Profile

MEDICAL HISTORY

You are Mr./Mrs. Phillips, a 72-year-old, with a new problem of midepigastric pain. You have been very healthy until one month ago when you started to have some mild midepigastric pain. You saw your physician, who told you it was most likely gastritis and prescribed an over-the-counter medication. The pain persisted, and, when you returned to see the physician, he seemed a bit more concerned, but said the pain was most likely from an ulcer or gallstones and scheduled you to have a computed tomography (CT) scan of the abdomen. You are now returning to the physician's clinic to hear the results of the CT scan.

SOCIAL HISTORY

You are divorced, have two children, ages 40 and 38 years. You live alone but have a "significant other" you have been seeing for two years. You are a retired commercial artist. Both of your parents are deceased, and you have one sister who lives in the area.

SETTING

Outpatient clinic office of your primary physician

TASK

Your partner, in the role of the physician, will break the bad news to you. Your demeanor should be mildly anxious. Once told that you likely have cancer, you may adopt one of several emotional reactions (quiet-introspective, disbelieving, angry, or other). Some

NOTES

questions and comments you may want to pose (or any others you think are appropriate) include the following:

- What does this mean?
- What can be done if it is cancer?
- Am I going to die?
- How can you be sure?
- Maybe the radiologist made a mistake.
- I want another opinion.
- Will I be in pain?

Information for Physician

MEDICAL HISTORY

You are caring for a previously healthy 72-year-old, Mr./Mrs. Phillips, with a new problem of abdominal pain. He/she has been a patient of yours for more than five years and came to see you one month ago with midepigastric pain. You thought it was most likely gastritis and prescribed an over-the-counter H₂ blocker. One week ago he/she returned saying the pain was getting worse, and, on examination, you noted left supraclavicular adenopathy. You ordered an outpatient CT scan of the abdomen because of suspicion of an abdominal malignancy. You reviewed the CT scan with the radiologist yesterday. It showed a focal mass with ulceration in the body of the stomach and numerous (more than 10) densities in the liver compatible with liver metastases. The radiologist believes that the findings are absolutely typical of metastatic stomach cancer. You decide the easiest way to confirm the diagnosis is a percutaneous liver biopsy of the one of the larger liver nodules, but you need to discuss the CT results first with the patient when he/she returns to your office.

SOCIAL HISTORY

Your patient is divorced, has two children, ages 40 and 38 years. The patient lives alone but mentioned to you that he/she has a "significant other." He/she is a retired commercial artist; both parents are deceased, but he/she has one sister who lives in the area.

SETTING

An examination room in your outpatient clinic

TASK

Present the CT scan information to your patient who has returned to your office to discuss the test results.

Giving Bad News Learner Assessment Form

Content Checklist: Make an “X” if the resident did this without prompting, mark with “✓” if the resident did this only after prompting, and leave blank if this was not done.

- ____ Greet the patient and introduce self
- ____ Explain the purpose of the meeting
- ____ Ask the patient his or her understanding of the issue
- ____ Give advanced warning of bad news
- ____ Describe the bad news in plain language; no jargon
- ____ Allow the patient to digest the information; uses silence
- ____ Offer an opportunity for the family member to ask questions
- ____ Respond to questions using plain language; no jargon
- ____ Offer a plan for next steps to follow meeting

Communication Skills— Please check one box per question using the following rankings:

- 3 = Excellent
- 2 = Good
- 1 = Marginally Satisfactory, and
- 0 = Unsatisfactory (poorly done or not done at all)

	3	2	1	0
Assures comfort and privacy				
Assumes a comfortable interpersonal communication distance				
Maintains an open posture				
Reflects patient’s emotions				
Displays empathy through words, expression, or touch that was appropriate to situation				
Reflects patients thoughts and concerns				

Please provide your overall assessment.

- ____ Competent to perform independently
- ____ Needs close supervision
- ____ Needs basic instruction

Do you believe the physician was able to present bad news with compassion in a manner so as to do no harm? Yes or No

If you believe additional training is needed, please indicate what problems need to be addressed (check all that apply):

- Basic communication skills (eye contact, rate of speech, excessive use of jargon, personal space)
- Professional attitude (sullen, not empathic, angry, giggles, or other, please describe in the space below)

- Other

NOTES

CHAPTER 16

Goals of Care/ Conducting a Family Conference

“The medical student may be sometimes a rough diamond; but when he comes to have personal charge of patients, and to have life and health of a fellow creature depending on his individual care, he becomes a changed man, and from that day forth his life becomes a constant exercise of beneficence.”

—Joseph Lister, MD

Learning Objectives

Attitudes

- Value the physician's role in convening family conferences.
- Value the patient's and family's role in working with the health care team.
- Aspire to enhance professional skills in conducting a family conference.
- Respect the patient's autonomy.

Knowledge

- Describe the physical setting where a family conference should be held.
- Understand who should be involved in a family conference.
- Understand the concepts of decision-making capacity and surrogate decision maker.
- Describe the key steps in running a family conference.
- Describe strategies for working with families when there is disagreement or indecision.
- Describe how to follow-up after a family conference.

Skills

- Demonstrate how to open a family conference.
- Demonstrate how to describe the concept of a surrogate decision-making and health care power of attorney.
- Demonstrate how to guide a discussion of the patient's medical status.
- Demonstrate how to moderate a discussion of treatment decision making.
- Demonstrate how to conclude a family conference.
- Write a complete note summarizing a family conference.

NOTES

Pre/Post Test

1. Describe three common reasons for convening a family conference concerning a nondecisional patient:
 - a. _____
 - b. _____
 - c. _____
2. Write the phrase you would use when asking a patient or family members their understanding of the patient's medical conditions.
“ _____ ”
3. List two key points when summarizing the medical condition.
 - a. _____
 - b. _____
4. List three steps to take when there is no clear family consensus about decisions.
 - a. _____
 - b. _____
 - c. _____

Answers

(1) Share information, set goals, resolve differences of opinion, support family coping, (2) “Can you tell me what the doctors have told you?” or “Can you tell me what your understanding is of <patient name>'s condition and treatment plan?” (3) present big picture, succinctly, no jargon, solicit questions, (4) set time-limited goals, arrange a follow-up meeting, remind family members of the concept of surrogate decision making and ask them to think about what decision the patient would make if able to speak for himself or herself, offer and recruit support for the family (chaplain; social worker; psychologist)

Teaching Outline

Establishing goals of care for seriously ill patients or patients near the end of life is a critical surgical skill. Such discussions can occur in the inpatient or outpatient setting and often occur during a family meeting. Convening a family conference is necessary whenever there is a need for discussion among key members of the health care team, the patient, the patient's family, and other essential family support people such as a member of the clergy or a close personal friend. A successful family conference is more likely to occur if key steps are completed, in the correct order; a 10-step process is outlined here. These 10 steps are not a cookbook or blueprint that can be followed in a rigid sequence, but a list of principles and tasks that a surgeon should consider incorporating during the family meeting. The process is similar to the principles for giving bad news. Because the history and needs of each patient and family are unique, it is important that the surgeon assess and respond to the family's needs during the meeting.

1. Premeeting Planning

Determine the reasons for convening a family conference.

- Review medical condition, set treatment goals, decide future level of care/treatments
- Establish surrogate decision maker
- Resolve patient, family and/or staff conflicts

Decide what is medically appropriate: What tests, procedures, and interventions do you believe will improve or worsen function, longevity, and quality of life?

Review medical history: Review all pertinent medical facts, including treatment options, prognosis, with and without treatment, and consultant opinions.

Coordinate opinions: Contact consultants to coordinate message to patient and family.

Advance directives: Review any advance directive documents and bring to the meeting.

Psychosocial data: Obtain all available information about the patient and family system, psychosocial status, and issues.

Attendees: Determine who you want to have present from the medical team, and invite the family to bring whomever they want to the

meeting. Determine whether there is a need for an interpreter for the patient or family members.

Meeting leadership: Designate one person from the medical team to serve as meeting leader.

Determine if the patient has decision-making capacity

- Decision-making capacity refers to the capacity to make medical decisions and to provide informed consent to treatment. This is different from *competence*, a legal term; competence is determined by a court, not by a physician.
- Key elements of decision-making capacity: A patient must meet three criteria to demonstrate decision-making capacity:
 - i. Ability to understand information about diagnosis and treatment
 - ii. Ability to evaluate, deliberate, weigh alternatives, and compare risks and benefits
 - iii. Ability to communicate a choice verbally, in writing, or with a nod or gesture

2. Environment

Find a quiet, private room; arrange chairs in a circle so each participant has a "front-row" seat; make sure the patient, if participating, will be as comfortable as possible.

3. Introductions

Ask all participants to introduce themselves and their relationship to the patient. For large groups, set ground rules: everyone can speak, no interruptions. Identify the legal surrogate decision maker if available. Review your goals and the purpose of the meeting; ask participants for their goals. Write names down if this is helpful to you.

4. Determine what the patient and family already know.

"What is your understanding of _____'s present condition?" "What have you been told about _____'s condition?" For patients with chronic diseases, ask about function and quality during the preceding three to six months and any changes or trends. Invite all participants to share their impressions.

NOTES

5. Medical review

Provide a short synopsis of the current medical condition and how the current condition fits within the larger illness trajectory (for patients with chronic disease). The synopsis should be very brief, focusing on the large overall condition (“Your grandfather has peritonitis, that is, severe infection in the abdomen, with kidney failure. He is in a coma.”). **Avoid medical jargon.** Use the word “dying” if appropriate to the situation; “Even if he has an operation at this point, it is too late to help because I believe he is dying.”

6. Allow silence; respond to questions and emotional reactions.

When the medical review has indicated that no further treatments are likely to reverse the disease process or the patient is dying, there are two common reactions:

- **Acceptance:** Patients and families who understand and accept that death is approaching will typically ask or be thinking of the following questions and emotional reactions:
 - i. How much time?
 - ii. What will happen?
 - iii. What do we do now?
- **Nonacceptance:** When patients or families are not ready to accept that death is coming, common questions include (see step 8, Managing Conflict):
 - i. How can you be sure?
 - ii. He was fine last week.
 - iii. We want a second opinion.
 - iv. There must be some mistake.
 - v. Shifting focus by asking questions about a relatively minor aspect of care

Common emotional responses: During this phase of the meeting, emotional reactions are common.

- Sadness
- Grief, tears, crying, wailing
- Guilt
- Anger
- Regret

7. Present broad care options.

You will need to discuss prognosis to help patients and families decide among care options. A good entry to such a discussion is: “Has anyone talked to you about time?” Guidelines on providing prognosis include the following: (a) Always ask if such a discussion is desired before providing data. (b) Provide data in a range (a few weeks to a few months). (c) Stop and allow silence after providing data to gauge any emotional reaction.

Options usually breakdown into two major domains:

- Continuing or expanding life-prolonging treatments with a goal of improved function, lengthened life, and/or improved quality
- Continuing comfort care, but discontinuation of life-prolonging treatments with expected death

When patients can speak for themselves

- Ask the patient what treatment he or she is considering.
- Ask the patient what type of support he or she would like from family members and the health care team.
- Invite discussion from other family members about supporting the patient’s decision.

When patients cannot speak for themselves

- Describe the goal of substituted decision making; to speak on behalf of the patient by making the choices we believe the patient would make if he or she could speak.
- Ask each family member what he or she believes the patient would choose if able to speak on his or her own behalf.
- Ask each family member what his or her own wishes are for the patient.
- At this point, some families want time alone (10 or 15 minutes) to talk before making a decision.

Making a Recommendation

When patients and families struggle to make a decision or you believe there is one preferred medical decision based on the facts and/or your knowledge of the patient’s wishes, **make a clear recommendation.** Avoid statements such as: “What would you like us to do?” This type of statement only tends to worsen a family’s sense of guilt about “pulling the plug.”

NOTES

8. Managing conflict

This is a point in the conference when conflicts between the family and the health care team or conflicts between family members typically surface, especially when the questions listed for nonacceptance are verbalized. Common reasons for such conflicts include the following:

- **Grief/time:** Family members have not had sufficient time to psychologically adjust to imagining their life without the dying person.
- **Information:** Incorrect, misleading, or conflicting information has been provided to the family by other health care providers.
- **Anger/guilt:** Long-lasting intrafamily issues may disrupt or preclude logical decision making; in severe cases, the struggle you observe may be the result of long-standing serious family dysfunction. Issues of past or current drug or alcohol dependence and/or physical, verbal, or sexual abuse are common.
- **Trust:** If a patient or family does not have trust in the medical team, it is impossible to work together to develop a treatment plan.
- **Culture:** Differences in culture, religion, socioeconomic status, and so forth may all impede decision making. See the chapter on cross-cultural issues for strategies.

Key points in managing conflict

- Active listening: Strive to maintain a civil discourse; ensure that your body language is open, conveying concern and empathy; restate or paraphrase what people are saying to make sure you and others understand.
- Correct any factual misunderstanding.
- Provide an empathic statement: “I can’t imagine how hard this must be.”
- Keep the focus of the discussion on the patient’s well-being
- Recognize that time may be necessary: Schedule a follow-up meeting.
- Establish a time-limited trial of continued life-sustaining treatments; establish clear goals and a time line (such as improved cognition, improved LFTs).
- Recognize that other resources may help the family: psychologist, spiritual counselor, palliative care team, ethics consultation.
- State directly that you (and health care team) will not abandon the patient and family and will ensure that the patient remains as comfortable as possible.

NOTES

9. Translate goals into a care plan.

When a decision has been made to limit further life-sustaining treatments, it is time to refocus the goals of care. Ask: “Knowing that time is short, what is important? What do you want or need to do in the time you have left?” Typical responses are home, comfort, being with family, and living until a particular life event.

Treatment goals drive our choice of diagnostic and therapeutic methods. When treatment goals change, it is natural that diagnostic and therapeutic methods will also change—some will be discontinued and others started. The phrase “withdrawing treatment” can have a powerful emotional impact on a patient and family because it may suggest abandonment. For this reason, the physician should not use this term but should instead speak about changing the goal of treatment from cure to maintaining the patient’s comfort. In addition, the provision or discontinuation of certain treatments such as nonoral hydration and nutrition can have strong emotional meaning. Therefore, the physician should facilitate discussion of these decisions and explore their meaning with patients and families.

Review the current medical tests, procedures, medications. Decide which are helping to meet the patient’s goals and which are providing no benefit. Key items for discussion at this time include the following:

- Future hospitalizations or intensive care unit admissions
- DNR status
- Use of artificial hydration/nutrition, blood products, or antibiotics
- Home support, hospice

Explore the meaning of changing treatment goals (and discontinuing some treatments) with the patient and family. Some issues are inherently more difficult than others to consider (hydration and feeding withdrawal are typically the hardest decisions for families). Be aware of cultural beliefs and attitudes that will influence decision making.

Develop a care plan that matches the goals of the patient and family, and verbally summarize the care plan to ensure understanding and agreement. Caution against unexpected outcomes (for example, if a dying patient does not die as expected following discontinuation of treatment).

10. Document and discuss

Discuss the meeting with health care providers who were unable to attend (for example, the patient’s evening nurse). Provide concise written documentation of the meeting: who was present, what was discussed, what was decided, what decisions were deferred, plan of care and next steps.

NOTES

Bibliography

Abbott KH, Sago JG, Breen CM, et al. Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support. *Crit Care Med*. 2001;29:197–201.

Ambuel B. Conducting a family conference. <http://www.eperc.mcw.edu/FastFactPDF/Concept%20016.PDF>. Accessed July 27, 2009.

Council Report: decisions near the end of life. *JAMA*. 1992;267:2229–2233.

Curtis JR. Communicating about end-of-life care with patients and families in the intensive care unit. *Crit Care Clin*. 2004;20:363–380.

Curtis JR, Engelberg RA, Wenrich MD, et al. Missed opportunities during family conferences about end-of-life care in the intensive care unit. *Am J Respir Crit Care Med*. 2005;171(8): 844–849.

Curtis JR, Patrick DL, Shannon SE, et al. The family conference as a focus to improve communication about end-of-life care in the intensive care unit: opportunities for improvement. *Crit Care Med*. 2001;29(2 suppl): N26N33.

Junkerman C, Schiedermaier D. *Practical Ethics for Students, Interns, and Residents*. Frederick, MD: University Publishing Group; 1994.

Lautrette A, Ciroldi M, Ksibi H, et al. End-of-life family conferences: rooted in the evidence. *Crit Care Med*. 2006;34(11): S364–S372.

Lautrette A, Darmon M, Megarbane B, et al. A communication strategy and brochure for relatives of patients dying in the ICU. *N Engl J Med*. 2007;356(5):469–478.

Lilly CM, De Meo DL, Sonna LA, et al. An intensive communication intervention for the critically ill. *Am J Med*. 2000;109:469–475.

Meisel A, Kuczewski M. Legal and ethical myths about informed consent. *Arch Intern Med*. 1996;156:2521–2526.

Quill TE, Brody H. Physician recommendations and patient autonomy: finding a balance between physician power and patient choice. *Ann Intern Med*. 1996;125:763–769.

Ruark JE, Raffin TA. Initiating and withdrawing life support: principles and practice in adult medicine. *N Engl J Med*. 1988;318:25–30.

Tracy MF, Ceronsky C. Creating a collaborative environment to care for complex patients and families. *AACN Clin Issues Crit Care Nurs*. 2001;12(3):383–400.

Weissman DE. Decision making at a time of crisis near the end of life. *JAMA*. 2004;292:1738–1743.

Establishing Treatment Goals | Role-Playing Exercise | Faculty Guide

1. Review and discuss the **Establishing Treatment Goals, Withdrawing Treatments** teaching outline.
2. Ask students to form pairs, and distribute the role-playing exercise.
3. Students should spend five to seven minutes role playing. The “patient” and “physician” should then independently complete an evaluation form and discuss their impressions of the interview. If there is time, have the students switch partners and change roles so everyone has the opportunity to role play the “physician.”
4. Debrief the experience with the entire group: good points, bad points, what worked well, what was less effective, what participants learned that they would apply in their work, and so forth.
5. You may choose to demonstrate your technique for this type of discussion using the case and choosing one student to play the role of the patient.

Case Blueprint

Purpose of case: Discussing treatment goals

Training level: Medical students, postgraduate trainees, or faculty.

Simulated patient name: Mr./Mrs. Williams

Diagnosis: Metastatic pancreatic cancer

Setting: Physician’s clinic office, surgeon

Reason for visit: To go over test results and discuss treatment goals

Time allotted: Seven minutes

Information for Surgeon

Medical History

Mr./Mrs. Williams is 59 years old, diagnosed with pancreatic carcinoma five months ago after a locally advanced, unresectable, pancreatic mass and painless jaundice were noted. The patient has been followed up in the surgery clinic for more than five months. He/she underwent surgery to relieve the biliary obstruction and then received radiation and two months of chemotherapy. The chemotherapy was very hard on him/her, causing severe nausea and fatigue. The patient called you three days ago saying that over the past three weeks, he/she has noticed a decline in energy, generalized fatigue, and little appetite. He/she has no pain or nausea. You ordered an abdominal computed tomography (CT) scan and asked him/her to come in today to go over the results.

The CT scan shows considerable tumor progression with multiple new liver metastases. You discuss the case with an oncologist who recommends no further chemotherapy because the patient tolerated the first treatments so poorly. The oncologist suggests that you refer the patient to a hospice program; he says the prognosis is two to four months.

The patient has mild hypertension controlled with medication and had one episode of renal colic three years ago.

Social History

The patient is married with two daughters, ages 28 and 24 years; both live in the area. The patient is an elementary school special education teacher on extended leave since the cancer surgery. The patient has never smoked and uses alcohol rarely.

Task

Enter the room and begin a discussion with Mr./Mrs. Williams. You have the following goals for this visit:

- Review CT scan results and the oncologist’s recommendations.
- Elicit the patient’s goals for the future.

NOTE: Do not discuss the issue of DNR orders or hospice referral in this exercise.

NOTES

Patient Profile

Medical History

I am Mr./Mrs. Williams and am 59 years old; I was diagnosed with pancreatic cancer five months ago after I developed jaundice and they found a big mass in my pancreas. After a needle biopsy was done, I had surgery to relieve my jaundice and then received radiation and two months of chemotherapy. I became very ill from the chemotherapy and resolved never to do that again. During the past 3 weeks, I noticed a decline in energy, increasing fatigue, and little appetite; I have no pain or nausea. I contacted the surgical clinic, after which my doctor ordered a CT scan. I am coming to the clinic today to get the CT scan results.

Social History

Family relationships and living situation: I am married and have two daughters, ages 28 and 24 years, who live in the area, they are both single.

Occupation: I am an elementary school special education teacher, on leave since the cancer was found. The work is very stressful but rewarding.

Hobbies and recreation: I sing in a community choir and like to grow vegetables.

Religion: I was raised Lutheran but am not involved with a church. I do believe in God and an afterlife.

Mood, Affect, and Demeanor

I appear anxious and sad. I know that the cancer has come back, but I still have hope of beating the cancer, especially since the doctors haven't actually come out and actually said that I'm dying. I am scared about what is happening, as I don't know what the future will bring.

Task and Responses to Surgeon

The "doctor" will be telling you the results of the CT scan—you are alone today; no one came with you to the doctor's office. If the doctor does not tell you the CT scan results within the first two minutes, you become increasingly anxious. If three minutes go by without the doctor telling the results, say, "Just tell me: what did the test show?" (or something similar). As soon as possible after the doctor tells you that the cancer is growing, ask: "Does this mean I need to start chemotherapy again? I really hate that."

If asked "What scares you most about this?" "What are you most afraid of?" or any questions like these questions, explain your fear of the unknown, not of being dead, but your fear of dying, and your sadness at not seeing your daughters married and with children.

If asked about your personal goals for the time remaining, say "I want to be kept comfortable and I don't want to be a burden on my family." "I'd like to be at home if possible."

NOTES

Learner Evaluation Tool | OSCE: Goals of Care

Content Checklist of skills: Make an "X" if the resident did this without prompting, mark with a "✓" if the resident did this only after prompting, and leave blank if this was not done.

- ____ Greets the patient/family member and introduces self.
- ____ Explains the purpose of the meeting.
- ____ Asks the patient/family member to describe understanding of the issue.
- ____ Describes the current medical condition succinctly without jargon.
- ____ Allows the patient/family member to digest the information; uses silence.
- ____ Offers an opportunity for the family member to ask questions.
- ____ Responds to questions using plain language, no jargon.
- ____ Discusses prognosis.
- ____ Describes treatment options.
- ____ Makes a recommendation, if appropriate.
- ____ Allows patient/family to describe goals.
- ____ Summarizes discussion.

Communication Skills— Please check one box per question using the following rankings:

- 3 = Excellent
- 2 = Good
- 1 = Marginally Satisfactory, and
- 0 = Unsatisfactory (poorly done or not done at all)

	3	2	1	0
Assures comfort and privacy				
Assumes a comfortable interpersonal communication distance				
Maintains an open posture				
Information provided is clear and unambiguous				
Allows family member time to reflect; does not rush discussion				
Reflects emotional meaning				
Displays empathy through words, expression, or touch that was appropriate to situation				

Please provide your overall assessment:

- ____ Competent to perform independently
- ____ Needs close supervision
- ____ Need basic instruction

Do you believe the physician able to present bad news with compassion in a manner so as to do no harm? Yes or No

If you believe additional training is needed, please indicate what problems need to be addressed (check all that apply):

- Basic communication skills (eye contact, rate of speech, excessive use of jargon, personal space)
- Professional attitude (sullen, not empathic, angry, giggles; other: please describe: _____)
- Other: _____

NOTES

CHAPTER 17

The DNR Discussion

“To save a man’s life against his will is the same as killing him.”

—Horace

Learning Objectives

Attitudes

- Reflect on personal attitudes and values surrounding DNR discussions.
- Consider DNR orders as one facet of advance directives, within the context of the patient's illness and other treatment goals, not as an isolated decision.

Knowledge

- Explain the ethical and legal principles guiding treatment withdrawal and a DNR discussion.
- Describe risks and benefits of CPR in different patient populations: healthy young adults; patients with metastatic cancer, renal failure, or multiorgan failure.
- Describe situations when it is appropriate to discuss treatment withdrawal and DNR orders.
- Describe the appropriate physical setting for DNR discussions.
- Describe the important first steps when discussing treatment withdrawal or DNR orders.
- Describe who should be present at discussions of DNR orders.
- Describe how to close a discussion of treatment withdrawal or DNR orders.
- Describe the steps to take when there is no consensus between physicians and patient and/or family.

Skills

- Demonstrate communication skills necessary to discuss DNR orders.
- Demonstrate skills necessary to describe the current medical care situation using appropriate language.
- Demonstrate ability to work with allied health professionals in planning a discussion of DNR orders.
- Demonstrate how to document the outcome of a DNR discussion in the medical record.

NOTES

Pre/Post Test

1. What is the physician's legal responsibility concerning DNR discussions?
2. List two statements to avoid during a DNR discussion.
 - a. _____
 - b. _____
 - c. _____
3. List three options for managing conflicts about DNR orders between physicians and patients and/or families.
 - a. _____
 - b. _____
 - c. _____

Answers

(1) most states, no legal guidelines, only hospital policies concerning the role of physicians in inquiring about a patient's CPR/DNR wishes, (2) Do you want us to do everything? What should we do if your heart stops? (3) allow time, seek out underlying reasons for the conflict, seek palliative care consultation

DNR discussions should be conducted within the context of a larger discussion reviewing overall patient condition, prognosis, and goals (see Chapter 16: Goals of Care).

Discussing DNR Orders

- Who needs a DNR order discussion? (in order of priority)
 - Inpatients with an advanced life-threatening illness (such as metastatic cancer, sepsis, acute stroke)
 - Inpatients with other “serious” chronic illnesses
 - Outpatients as part of routine advanced directive discussion
 - For inpatients with non–life-threatening conditions or diseases (such as delivery of neonate, simple infections), CPR is assumed in the unlikely event of a medical catastrophe requiring resuscitation.
- Who should participate in a DNR order discussion?
 - The decisional patient together with physician of record
 - Others may participate and be of assistance: family, friends, social worker, nurse, chaplain
- Cardiopulmonary resuscitation: benefit vs burden
 - Primary indication for resuscitation is cardiopulmonary arrest due to an acute event (such as myocardial infarction or pulmonary embolism).
 - Overall, 15 percent of in-hospital CPR attempts lead to hospital discharge. Predictors of poor outcome include metastatic cancer, sepsis, multiorgan failure, CPR event longer than 30 minutes.
 - Burdens of CPR include permanent vegetative state (10%), chest wall trauma (25%–50%), cost, prolonging the dying process in an expected death from a chronic disease.

Conducting the DNR Discussion

1. Physical setting
 - Quiet, comfortable room, turn off beeper and other personal electronic devices, check personal appearance
 - Make sure you understand prognosis and treatment options.
 - Ask the patient or legal decision maker who he or she would like have participate.
 - Have participants, including yourself, sitting down.
 - Decide if you want others present (such as nurse, chaplain, social worker) and obtain patient’s permission.
2. First steps
 - Ask if the patient has ever completed an advance directive.
 - Determine if the patient is decisional.
 - Before initiating a discussion with the patient, family, and/or surrogate, clarify in your own mind whether you think CPR is an appropriate medical intervention, at this time, for this patient, given the current medical condition.
 - Determine what the patient knows: “What is your understanding of your present condition?” or “What have the doctors told you about your condition?”

NOTES

3. Discuss DNR in the context of overall goals of care (see Chapter 16: Goals of Care) Review with the patient his or her current medical condition and expected prognosis.

- Review with the patient your overall treatment plan.
- Discuss the relative benefits and/burdens of CPR within the context of the patient's current condition and personal goals. As part of this discussion provide your professional, evidence-based opinion:
 - i. if you believe that CPR *is not* medically indicated, this belief should be expressed to the patient as one aspect of the overall treatment plan, stressing the positive things that will be done, for example, "Your cancer is growing despite the latest chemotherapy. I am recommending no further chemotherapy but I will provide you with maximal treatments for your pain or any other symptoms you may experience. I do not recommend the use of breathing machines or other artificial means to prolong your life. I do recommend a variety of interventions to help you remain comfortable and be as active as possible."
 - ii. if you believe that CPR *is* medically indicated, you may express this opinion to the patient.
 - iii. If you are uncertain about the benefits of CPR, you should tell the patient that CPR may or may not be of benefit and describe the range of benefits and burdens.
- Reinforce that DNR does not mean *do not treat*; it applies only to CPR.

4. Statements to avoid during the DNR discussion:

- What would you like us to do if your heart stops?
- Do you want us to do everything?
- Do you want us to start your heart if it stops?
- If we do CPR, we will break your ribs and you will need to be on a breathing machine. You don't want us to do that, do you?

5. Documentation

- Review DNR discussion with involved staff, for example, nurse, social worker.
- Write a DNR order in medical record.

- Write a progress note: include participants at discussion, indications for DNR order, role of consultants, and the decision-making capacity of the patient or the authority for use of a surrogate (see discussion of surrogate decision making).

6. Managing patient-family-physician DNR order conflicts

- Review overall patient prognosis and treatment goals with patient and family.
- Clarify patient and family misconceptions that may exist about the nature and purpose of CPR.
- Use time as an ally—allow patient and family to consider options.
- Ask other patient advocates, such as family, friends, clergy, nurses, social workers, to become involved.
- Be aware of reasons for a seemingly irrational DNR request: unrealistic goals, guilt, confusion concerning the therapeutic plan, mistrust of the physician, family differences, ethnic or sociocultural differences, language barriers.
- Consider palliative care or ethics consultation.

7. Continued conflict: Physician options

- Decide if you believe that CPR represents a futile medical treatment, that is, CPR cannot be expected to restore cardiopulmonary function or to achieve the expressed goals of the patient.
- If you believe that the patient or family is requesting a futile treatment and you have tried all the options suggested, you still have options:
 - i. A physician is not legally or ethically obligated to participate in a futile medical treatment
 - ii. In some facilities, a physician may enter a DNR order in the chart (may require one or two other physicians to review case and concur depending on local policy). The physician must instruct the patient or decision maker of the decision and rationale and, in some cases, hospital administration.
 - iii. You may transfer care to another physician chosen by the patient or family.

NOTES

Bibliography

- Blackhall LJ. Must we always use CPR? *N Engl J Med.* 1987;317:1281–1282.
- Ebell MH, Becker LA, Barry HC, et al. Survival after in-hospital **cardiopulmonary resuscitation**: a meta-analysis. *J Gen Intern Med.* 1998;13(12):805–816.
- Ebell MH. Practical guidelines for do-not-resuscitate orders. *Am Fam Phys.* 1994;50(6):1293–1299.
- Guidelines for the appropriate use of do-not-resuscitate orders. *JAMA.* 1991;265:1868–1871.
- Quill TE, Brody H. Physician recommendations and the patient autonomy: finding a balance between physician power and patient choice. *Ann Intern Med.* 1996;125:763–769.
- von Gunten CF, Weissman DE. Fast Fact and Concept #023: DNR orders in the hospital—part 1. 2nd ed. July 2005. Available at: http://www.eperc.mcw.edu/fastFact/ff_023.htm. Accessed July 27, 2009.
- von Gunten CF, Weissman DE. Fast Fact and Concept #024: DNR orders in the hospital setting—part 2. 2nd ed. July 2005. Available at: http://www.eperc.mcw.edu/fastFact/ff_024.htm. Accessed July 27, 2009.
- Waisel DB, Truong RD. The cardiopulmonary-resuscitation-not-indicated order: futility revisited. *Ann Intern Med.* 1995;122:304.
- Weissman DE. DNR orders: a call for reform. *J Palliat Med.* 1999;2:149–152.

Role-Playing Exercise | Faculty Guide

1. Review and discuss the **DNR Discussion** teaching outline.
2. Ask students to form pairs, and distribute the role-playing exercise.
3. Students should spend five to seven minutes role playing. The “patient” and “physician” should then independently complete an evaluation form and discuss their impressions of the interview. If there is time, have the students switch partners and change roles so everyone has the opportunity to role play the “physician.”
4. Debrief the experience with the entire group: good points, bad points, what worked well, what was less effective, what was learned that participants would apply in their work, and so forth.
5. You may choose to demonstrate your technique for this type of discussion using the case and choosing one student to play the role of the patient.

Case Blueprint

Purpose of case: Discussing DNR orders

Training level: Medical students, postgraduate trainees, or faculty

Simulated patient name: Mr./Mrs. Williams (same patient as in role playing about treatment goals)

Diagnosis: Metastatic pancreatic cancer

Setting: Hospital room

Reason for visit: Discuss goals and DNR orders

Time allotted: Seven minutes

Information for Physician

MEDICAL HISTORY

Mr./Mrs. Williams is a 50-year-old diagnosed with pancreatic carcinoma five months ago after a locally advanced, unresectable, pancreatic mass and painless jaundice were found. He/she underwent surgery to relieve the biliary obstruction and then received radiation and two months of chemotherapy. The chemotherapy was very hard on him/her, causing severe nausea and fatigue. He/she called you one week ago saying that during the past three weeks, there was a decline in energy, generalized fatigue, and little appetite. He/she has no pain or nausea. You ordered an abdominal computed tomography (CT) scan that showed new liver metastases. You met the patient last week to review treatment options; the patient elected not pursue any further chemotherapy, that his/her goal was to remain at home and be as comfortable as possible. However, yesterday, he/she called and said the pain was much worse and he/she was vomiting and unable to keep food down. The patient was admitted yesterday for pain and nausea management. Overnight, he/she did much better and today is taking clear liquids with much less pain.

The patient has mild hypertension controlled with medication and had one episode of renal colic three years ago.

NOTES

SOCIAL HISTORY

Patient is married with two daughters, ages 28 and 24 years, and both live in the area. The patient is an elementary school special education teacher on extended leave since the cancer surgery. The patient has never smoked and uses alcohol rarely.

TASK

Enter the “hospital” room and begin a discussion with Mr./Mrs. Williams; you have the following two goals for this visit:

1. Reaffirm the patient’s goals for future care.
2. Discuss CPR/DNR orders.

NOTE: Do not discuss the issue of hospice referral in this exercise.

Patient Profile**Medical History**

I am Mr./Mrs. Williams and am 59 years old; I was diagnosed with pancreatic cancer five months ago after I developed jaundice and they found a big mass in my pancreas. After a needle biopsy was done, I had surgery to relieve my jaundice and then received radiation and two months of chemotherapy. I became very ill from the chemotherapy and resolved never to do that again. During the past 3 weeks, I noticed a decline in energy, increasing fatigue, and little appetite. I contacted my surgeon who ordered an abdominal CT scan. Last week, I came to his/her clinic and was told that the cancer was progressing and that further chemotherapy would be of little benefit. My surgeon asked me about my goals for the time I had left. I indicated a desire to be kept comfortable and to be at home.

Two days ago, I began having increasing abdominal pain, nausea, and vomiting; yesterday, my surgeon admitted me to the hospital for pain and nausea control. He/she started some new medication, and I feel much better today, I am hoping to go home by tomorrow. I ate breakfast today; the pain is much better.

Social History

Family relationships and living situation: I am married and have two daughters, ages 28 and 24 years, who live in the area; they are both single.

Occupation: I am an elementary school special education teacher on leave since the cancer was found. The work is very stressful but rewarding.

Hobbies and recreation: I sing in a community choir and like to grow vegetables.

Religion: I was raised Lutheran but am not involved with a church. I do believe in God and an afterlife.

Mood, Affect, and Demeanor

I appear in my normal mood, fairly cheerful since I feel much better today. However, this recent pain and nausea was scary; I don’t know what the future will bring.

Task and Responses to Surgeon

Your surgeon will be coming to visit you. He/she will ask you to reaffirm your goals for the time remaining; say “I want to be kept comfortable, and I don’t want to be a burden on my family.” “I’d like to be at home if possible.”

If the surgeon asks you about CPR and DNR, be sure to ask him/her to explain any terms you don’t think an average patient would understand. After you believe you understand the question, ask the surgeon:

- If I get better in the coming days, can you change the order?
- Will you still be my doctor even if I decide I want to go on “life support”?

The surgeon may make a recommendation about CPR; tell the surgeon that you do *not* want to be resuscitated.

NOTES

DNR Discussion Learner Assessment Form

Make an "X" if the resident did this without prompting, make a "✓" if the resident did this only after prompting, and leave blank if this was not done.

- ____ Greets the patient and introduces self
- ____ Explains the purpose of the meeting
- ____ Asks the patient member to describe his or her understanding of the illness
- ____ Describes the current medical condition succinctly without jargon
- ____ Allows the patient to digest the information; uses silence
- ____ Offers an opportunity for the patient to ask questions
- ____ Responds to questions using plain language, no jargon
- ____ Discusses prognosis and treatment options
- ____ Asks patient to describe goals
- ____ Discusses CPR within the context of the disease, and prognosis and patient-defined goals
- ____ A clear recommendation regarding CPR or no CPR is made
- ____ Summarizes discussion

Communication Skills: Please check one box per question using the following rankings:

- 3 = Excellent
- 2 = Good
- 1 = Marginally Satisfactory, and
- 0 = Unsatisfactory (poorly done or not done at all)

	3	2	1	0
Assures comfort and privacy				
Assumes a comfortable interpersonal communication distance				
Maintains an open posture				
Reflects emotional meaning				
Displays empathy through words, expression, or touch that was appropriate to situation				

Please provide your overall assessment:

- ____ Competent to perform independently
- ____ Needs close supervision
- ____ Need basic instruction

Do you believe the physician was able to discuss DNR with compassion in a manner so as to do no harm? Yes or No

If you believe additional training is needed, please indicate what problems need to be addressed (circle all that apply):

- Basic communication skills (eye contact, rate of speech, excessive use of jargon, personal space)
- Professional attitude (sullen, not empathic, angry, giggles other, please describe: _____)
- Other: _____

NOTES

CHAPTER 18

Palliative and Hospice Care and Referrals

“An impaired profession is one whose virtues of courage, veracity, fidelity, dedication, including the social virtue of caring, are threatened by the external goods of power, prestige, and money, and whose identified purpose fails to unite its members.”

—Krizek T. Ethics and philosophy lecture: Surgery...is it an impairing profession?
Presented at the American College of Surgeons 87th Clinical
Congress, New Orleans, LA, October, 2001.

Learning Objectives

Attitudes

- Reflect on the meaning of referring a patient for palliative care or hospice services. What attitudes come to mind?
- Understand that surgeons need to take a leadership role in referring patients for palliative or hospice care.
- Understand that surgeons need to continue to have a presence in patient care once a patient is receiving palliative care or enrolled in a hospice program.

Knowledge

- Describe the meaning of the terms palliative care and hospice.
- Describe the benefits to patient and family of being in a home hospice program.
- Describe the members and functions of the palliative care or hospice core team.
- Describe the patient care responsibilities of the referring surgeon and the hospice medical director.
- Describe the role of the referring surgeon in developing the “plan of care” with the hospice team.
- Describe the key features of the Medicare Hospice Benefit, including eligibility criteria, physician role, covered services, care settings, and revocation rules.
- Describe prognostic factors for cancer, end-stage heart disease, liver failure, kidney disease, lung disease, dementia, and critical illness.
- Describe common patient and family reactions to the concept of palliative care and hospice care.

Skills

- Demonstrate communication skills in discussing palliative care or hospice referral with a patient and family.
- Demonstrate how to respond to patient and family concerns raised by a palliative care or hospice referral.
- Demonstrate how to contact a home hospice agency for the purpose of patient referral.

NOTES

Pre/Post Test

1. Describe the meaning of the term *palliative care*:

2. Describe the meaning of the term *hospice care*:

3. The most common setting where patients in the United States receive hospice care is in (hospital, nursing home, home, inpatient hospice, and so on):

4. List two eligibility criteria for hospice care under the Medicare Hospice Benefit:

5. List two prognostic factors in patients with cancer that predict a 3-month or less prognosis:

Answers

(1) interdisciplinary care that aims to relieve suffering and improve the quality of life for patients with advanced illness and their families, (2) a program of interdisciplinary care to support patients and their families through the dying process, (3) home, (4) physician-certified prognosis, treatment goals palliative rather than curative, (5) hypercalcemia, carcinomatous meningitis, ECOG of 3 or more

Palliative Care—Definition

The term palliative care was coined by Canadian surgeon Balfour Mount in 1975. Palliative care is interdisciplinary care that aims to relieve suffering and improve the quality of life for patients with critical, advanced, or terminal illness, and their families. It is offered simultaneously with all other appropriate medical treatment. No specific therapy is excluded from consideration, including surgical intervention. The indication for palliative care is based on the need to achieve quality-of-life goals, not a poor prognosis. The test of palliative care lies in the patient-caregiver agreement that the expected outcome is relief from distressing symptoms, easing of pain, and improvement in quality of life. The decision to intervene is based on the treatment's ability to meet the stated goals, rather than its effect on the underlying disease.

Hospice care (defined later) is a subset of palliative care in the United States, applying to the care of patients who meet eligibility criteria for hospice services (see later text). There are no eligibility criteria for palliative care services.

Surgical Palliative Care—Definition

Surgical palliative care is the treatment of suffering and the promotion of quality of life for seriously or terminally ill patients receiving surgical care (Cameron JL, ed. *Current Surgical Therapy*. 9th ed. Philadelphia, PA: Mosby, Inc; 2007).

Palliative Care—Principles

- Effective pain and nonpain symptom management
- Communication among patients, families, and provider teams
- Continuity of care across a range of clinical settings and services
- Interdisciplinary team-based care planning that involves the patient and family
- Attention to spiritual comfort
- Psychosocial support for patients and families
- Bereavement support for families of patients who die and for team members who provided care to the deceased

Surgical Palliative Care—Principles

- Emphasis on providing palliative care alongside curative care
- Understanding when transition from one model to the other is appropriate
- Use of procedural skills appropriately for palliation, as well as for cure

Who Provides Palliative Care Services and Where

Apart from hospice programs, palliative care services are provided in hospitals as consultation services or dedicated inpatient units, in outpatient settings, and in some long-term care facilities. Services are provided by an interdisciplinary palliative care team, with the palliative care physician, nurse, social worker, and chaplain as the core team members.

The most common point of interface for surgeons will be with a hospital-based palliative care consultation team.

Indications for consultation include the following:

- Assistance with complex pain and symptom management
- Assistance in goal-of-care discussions and decisions
- Prognostication and/or hospice eligibility assessment
- Psychological and spiritual support for patients and families
- Assistance in discussions and symptom management around withdrawal of life-sustaining interventions

In some settings, palliative care physicians assume attending physician duties, if requested; in others, they are strictly consultants; either way, these physicians can bill and receive payment through traditional Evaluation and Management codes.

NOTES

Hospice Services

Hospice is primarily a *philosophy* of care for dying patients and their families, focusing on control of distressing physical symptoms, psychological and spiritual support for the patient-family unit, and bereavement care after the patient's death. The term hospice is also used to describe the physical venue or agency of hospice care; and, in the United States, hospice is the name of the health benefit for terminal care. Hospice uses the concept of interdisciplinary care, realizing that no single health care professional can meet the needs of dying patients and families. Hospice care, limited to end of life, is a subset of palliative care.

Who Provides Hospice Services and Where

- **Medicare-certified home hospice agency:** Most common setting in the United States, often combined with a home health agency; a Medicare-certified hospice agency must provide 80 percent of total care days per year in the home setting (all agency patients combined); under the Medicare benefit, patients are eligible for inpatient care for symptoms that cannot be managed in the home (for example, pain that is out of control), or for respite care (up to 5-day inpatient stay)
- **Non-Medicare-certified home hospice agency:** Typically small, rural hospice programs
- **Inpatient beds within an acute care hospital:** (a) Beds used by a Medicare-certified home hospice agency for inpatient or respite care; (b) Provision by an acute care hospital of non-Medicare-certified hospice services, often by staffing a dedicated geographic nursing unit for care that follows the hospice philosophy
- **Nursing home:** May serve as a patient's primary place of residence and provide Medicare-certified hospice care when a contract for services exists between the nursing home and a Medicare-certified home hospice agency
- Free-standing dedicated inpatient hospice facility

Eligibility for Hospice Services

To be eligible for hospice services under the Medicare Benefit (see later text), patients must meet the following criteria:

- Physician-certified prognosis less than 6 months assuming "*the terminal illness runs its normal course*;" any terminal diagnosis is appropriate
- Treatment goals palliative rather than curative
- A physician willing to be identified as the physician-of-record

NOTE: Other eligibility criteria *may* exist, determined solely by the particular hospice agency (see "Miscellaneous Care Issues").

NOTE: Medicare-certified hospice agencies *may not* use DNR status as a criterion for hospice admission per the Center for Medicare and Medicaid Services.

Hospice Services

- Physical symptom control of pain, nausea, dyspnea, and so on
- Home health aide services for help with bathing, dressing, feeding
- Psychological counseling for patient, family, community
- Preparation for death, including completion of advanced directives, wills, funeral planning
- Spiritual support for patient and family before death and family after death
- Volunteers to assist patient and family
- Bereavement program for family after death

NOTES

Hospice Reimbursement

Medicare Hospice Benefit

1. When eligible (see above), a patient “signs off” of Medicare Part A (hospital payment) and signs on (elects) the Medicare Hospice Benefit.
2. There are three hospice benefit periods: The first two periods are each 90 days; the third benefit period is indefinite, consisting of unlimited 60 day periods. At the start of each benefit period, the patient must be recertified as hospice-eligible. The patient must meet the aforementioned criteria listed by two physicians, one of whom is typically the hospice medical director. During any benefit period, patients may revoke their hospice benefit and return to Medicare Part A; patients may subsequently return to the hospice benefit if they meet criteria (see above).

NOTE: The Medicare-certified hospice agency is responsible for the *Plan of Care*; all treatment decisions must be discussed and approved by the hospice care team, which includes representatives from the following mandated services:

- Hospice physician medical director
 - Skilled nurse (typically serves as overall case manager)
 - Social worker and chaplain
 - Volunteer program and bereavement program coordinators
3. The Medicare Hospice Benefit *does not* provide 24-hour custodial care.
 4. Patients may continue to use services of their primary physician for in-office or at-home visits; the primary physician can bill for services under Medicare Part B. The hospice physician medical director is available for consultation but does not assume direct care responsibilities and cannot bill Medicare for services to individual hospice patients.

5. Each day the patient is enrolled in the Medicare Hospice Benefit, the hospice agency receives reimbursement (approximately \$126/d). This reimbursement is used to support the salaries of the core team and the following additional services:

- Home health aide visits, as often as daily
- All drugs related to the terminal illness
- All durable medical equipment such as bed, commode, and so on
- Any ordered physical therapy, dietary counseling, and so on
- Payment for other medical services approved by the hospice team, such as palliative care
- Radiation, parenteral hydration, and so on

Other Payment Sources

- Most states administer a Medicaid Hospice program that is similar to the Medicare Benefit.
- Many private health insurers and health maintenance organizations have a hospice benefit that may include some or all of the features of the Medicare Benefit; for insurers without a hospice benefit, payment for per diem hospice services to a hospice agency can usually be negotiated on a case-by-case basis.

NOTES

Miscellaneous Care Issues

Beyond good physical, psychological, and spiritual care, there are a number of “gray” areas of palliative support services that can arise. These gray areas include the use of expensive and/or invasive treatment approaches for which the palliative value is often not clear. Each hospice agency is free to develop its own policy regarding the acceptability of these services for its patients. These services include the following:

- Blood products, cancer chemotherapy, and hormonal therapy
- Surgical interventions for palliation of symptoms (wound debridement, fixation of pathologic fracture)
- Nonoral feeding (nasogastric tube, G-tube, total parenteral nutrition), parenteral hydration
- Kidney dialysis or mechanical ventilation
- Antibiotics, oral or parenteral

Prognostic Indicators to Assist in Determining Hospice Eligibility

<14 Days: Actively Dying or Syndrome of Imminent Death

- Anuric—no dialysis planned
- Delirium
- No or minimal oral intake
- Cheyne-Stokes respirations, mottled skin, cool extremities
- Pooled oropharyngeal secretions (death rattle)

Three Months or Less

- In bed more than 50 percent of the time (performance status: ECOG, 3 or more; Karnofsky, <50)
- Hypercalcemia (Ca) (except newly diagnosed myeloma or breast cancer)
- Dyspnea (HIV, Ca)
- Carcinomatous meningitis or malignant pericardial effusion
- Liver metastases with jaundice

Six Months or Less

- Multiple brain metastases
- Metastatic solid cancers: no treatment planned or none effective (except breast or prostate cancer)
- Malignant ascites or pleural effusion
- Severe dementia: no speech, bed bound, incontinent
- Central nervous system lymphoma (HIV)
- Congestive heart failure, chronic obstructive pulmonary disease (COPD)
- Symptomatic despite maximal treatment
- Weight loss
- Frequent hospitalization
- Rest dyspnea, tachycardia

NOTES

Other Indicators Suggestive of Potential Hospice Eligibility for Patients with Noncancer Diagnoses

Palliative Prognostic Scale (PaP)

- Uses the Karnofsky Performance Score (KPS) and five other criteria to generate a numeric score inversely related to survival (0–17.5).
- Validated for solid tumors and, in smaller studies, for organ failure syndromes, AIDS, and neurodegenerative disorders for predicting a survival time frame within 30 days.

Palliative Prognostic Score (PaP)		
Criterion	Assessment	Partial Score
Dyspnea	No	0
	Yes	1
Anorexia	No	0
	Yes	1.5
Karnofsky Performance Status (KPS)	>30	0
	10–20	2.5
Clinical prediction of survival (weeks)	>12	0
	11–12	2
	7–10	2.5
	5–6	4.5
	3–4	6
	1–2	8.5
Total WBC	<8.5	0
	8.6–11	0.5
	>11	1.5
Lymphocyte %	20%–40%	0
	12%–19.9%	1
	<12%	2.5
RISK GROUP	30-DAY SURVIVAL	TOTAL SCORE
A	>70%	0–5.5
B	30%–69%	5.6–11
C	<30%	11.1–17.5

Heart Failure

- Recent cardiac hospitalization (triples 1-year mortality)
- Elevated blood urea nitrogen level (defined by upper limit of normal) and/or creatinine level of 1.4 mg/dL (120 μmol/L) or more
- Systolic blood pressure less than 100 mm Hg and/or pulse more than 100 beats per minute (each doubles 1-year mortality)
- Ejection fraction less than 20 percent
- Decreased left ventricular ejection fraction (linearly correlated with survival at LVEF ≤45%)
- Ventricular dysrhythmias, treatment-resistant
- Anemia (each 1-g/dL reduction in hemoglobin associated with a 16% increase in mortality)
- Hyponatremia ($\text{Na}^+ \leq 135\text{--}137$ mEq/L).
- Cachexia
- Reduced functional capacity
- Comorbidities: diabetes, depression, COPD, cirrhosis, cerebrovascular disease, cancer, and HIV-associated cardiomyopathy

Decompensated Chronic Liver Failure

- *Model for End-stage Liver Disease (MELD)*
- MELD more objective than Child-Turcotte-Pugh. Used to determine survival benefit from TIPS, organ allocation for liver transplantation, and, more recently, survival prediction
- Uses serum creatinine and total bilirubin levels and international normalized ratio
- Calculator for MELD can be accessed at: <http://www.unos.org/resources/meldPeldCalculator.asp>

MELD Score and Survival			
MELD Score	Predicted 6-month survival	Predicted 12-month survival	Predicted 24-month survival
0–9	98%	93%	90%
10–19	92%	86%	80%
20–29	78%	71%	66%
30–39	40%	37%	33%

NOTES

Bibliography

- Beresford L, ed. *The Hospice Handbook: A Complete Guide*. Boston, MA: Little Brown and Co; 1993.
- Lassauniere JM, Vinant P. Prognostic factors, survival, and advanced cancer. *J Palliat Care*. 1992;8(4):52–54.
- National Hospice Organization. *Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases*. 2nd ed. National Hospice Organization; 1996.
- Turner R, Rosielle D. Fast Fact and Concept #082: Medicare Hospice Benefit Part I: Eligibility and Treatment Plan. 2nd ed. End-of-Life Physician Education Resource Center. Available at: http://www.eperc.mcw.edu/fastFact/ff_82.htm. Accessed July 23, 2009.
- Turner R, Rosielle D. Fast Fact and Concept #087: Medicare Hospice Benefit Part II: Places of Care and Funding. 2nd ed. End-of-Life Physician Education Resource Center. Available at: http://www.eperc.mcw.edu/fastFact/ff_87.htm. Accessed July 23, 2009.
- Turner R, Rosielle D. Fast Fact and Concept #090: Medicare Hospice Benefit Part III: Special Interventions. 2nd ed. End-of-Life Physician Education Resource Center. Available at: http://www.eperc.mcw.edu/fastFact/ff_090.htm. Accessed July 23, 2009.
- Wilner LS, Arnold R. Fast Fact and Concept #124: The Palliative Prognostic Score (PaP). October 2004 . End-of-Life Physician Education Resource Center. Available at: http://www.eperc.mcw.edu/fastFact/ff_124.htm. Accessed July 23, 2009.
- Reisfield GM, Wilson GR. Fast Fact and Concept #143: Prognostication in Heart Failure. September 2005; revised October 2006. End-of-Life Physician Education Resource Center. Available at: http://www.eperc.mcw.edu/fastFact/ff_143.htm. Accessed July 23, 2009.
- Dolan B, Arnold R. Fast Fact and Concept #189: Prognosis in Decompensated Chronic Liver Failure. September 2007. End-of-Life Physician Education Resource Center. Available at: http://www.eperc.mcw.edu/fastFact/ff_189.htm. Accessed July 23, 2009.

Role-Play Exercise | Faculty Guide

1. Ask participants to list three common reasons why a patient or family would be resistant to enrolling in home hospice care.
2. Ask participants to list three reasons why it is beneficial to the physician for his or her dying patient to be enrolled in a home hospice program.
3. Review the outline—**Hospice Care and Referrals**
4. Divide the group into triads (patient, wife, and physician) and ask each pair to practice discussing a hospice referral using the **role playing** case; after about 5 or 10 minutes, prompt the pairs to switch roles.
5. In a large group, ask for feedback on the interview. How did it go? What challenges do they anticipate incorporating this information into their interview? Does anyone have a particular way of discussing hospice care to share with the group?

Case Blueprint

Purpose of Case: Discussing the option of home hospice care

Training Level: Medical students, postgraduate trainees, or faculty

Simulated Patient Name: Mr./Mrs. Adams

Diagnosis: Pulmonary fibrosis

Setting: The patient's hospital room

Reason for Visit: To discuss home hospice care

Time Allotted: 7 minutes

Patient Profile

Medical History

I am Mr./Mrs. Adams, a 68-year-old patient in the hospital for the past 4 days. I was admitted with end-stage COPD and lung cancer. This hospital admission is my fourth in the past 3 months, all for dyspnea. With high-dose steroid treatment and respiratory treatments, I get a little better, but only for a short time. This time I was admitted to the thoracic surgical service for VATS for treatment of a recurrent pleural effusion. My functional ability is bed to chair with assistance. I've lost 20 pounds in the past 4 months. I have previously expressed a wish to my doctor for No Code status and no ICU admissions.

Social History

I live at home with my spouse of 41 years who is in good health; I live in a two-story home. I have two grown children, both married with children, who live in the metropolitan region. I am a nonobservant Catholic, not connected with a church. I am a retired accountant, and my spouse works part-time at a hardware store.

NOTES

Setting

I am in a chair, next to the hospital bed. My spouse is with me when the doctor comes in the room.

Task

Your doctor will be coming to discuss a referral for home hospice care.

SOME QUESTIONS YOU MAY POSE TO THE DOCTOR:

- Does this mean you will no longer care for me?
- Does this mean I can't come back to the hospital?
- What happens if my breathing gets bad at night—do I just call 911?
- I'm not sure I want someone coming into my home.

AS THE SURGEON TALKS TO YOU ABOUT HOSPICE CARE, THINK ABOUT THESE QUESTIONS:

- What emotional reactions are elicited by the term *hospice*?
- What are your concerns and fears about home hospice care?

Information for the Surgeon

Medical History

Mr./Mrs. Adams is a 68-year-old patient on your inpatient service for the past 4 days who admitted with end-stage COPD and advanced lung cancer. This time the patient is admitted to the thoracic surgical service for VATS for treatment of a recurrent pleural effusion. The patient has had no consistent relationship with specialists or a personal physician. This hospital admission is the fourth in the past 3 months, all for dyspnea. He/she has severe hypoxemia and mild hypercarbia. With high-dose steroid treatment and respiratory treatments, there is some short-term improvement in the dyspnea. His/her functional ability has declined during the past 6 months dramatically—currently it is bed to chair with assistance; there has been a 20-pound weight loss in the past 4 months. The patient has previously expressed a wish for No Code status and no ICU admissions.

Social History

The patient lives at home with a spouse of 41 years who is in good health. When you last spoke with the spouse, he/she was very anxious, asking about newer experimental treatments. They live in a two-story home. They have two grown children, both married with children, who live in the metropolitan region. They are nonobservant Catholics, not connected with a church. The patient is a retired accountant, and the spouse works part-time in a hardware store.

Setting

The patient will be sitting in a chair in the hospital room, and the spouse is with him/her.

Task

You will role-play the surgeon who enters the patient room to discuss home hospice care. Your task is to bring up the subject of hospice care, tell the patient/spouse that you think it is time to begin home hospice services, and answer any questions they have.

NOTES

Hospice Discussion Assessment Form

Make an “X” if the resident did this action without prompting, make a “ü” if the resident did this action only after prompting, and leave blank if this action was not done.

- ____ Greet the patient member and introduces self.
- ____ Explain the purpose of the meeting.
- ____ Ask the patient member to describe his or her understanding of the illness.
- ____ Describe the current medical condition succinctly without jargon.
- ____ Allow the patient to digest the information, uses silence.
- ____ Offer an opportunity for the patient to ask questions.
- ____ Respond to questions using plain language, no jargon.
- ____ Discuss prognosis and treatment options.
- ____ Ask patient to describe goals.
- ____ Discuss the role of hospice care within the context of the particular case and prognosis.
- ____ Provide a clear recommendation about hospice care.
- ____ Summarize discussion.

Communication Skills: Please check one box per question using the following rankings:

- 3 = Excellent
- 2 = Good
- 1 = Marginally Satisfactory, and
- 0 = Unsatisfactory (poorly done or not done at all)

	3	2	1	0
Assures comfort and privacy				
Assumes a comfortable interpersonal communication distance				
Maintains an open posture				
Reflects emotional meaning				
Displays empathy through words, expression, or touch that is appropriate to situation				

Please provide your overall assessment:

- ____ Competent to perform independently
- ____ Needs close supervision
- ____ Needs basic instruction

Do you believe the surgeon is able to discuss hospice with compassion in a manner so as to do no harm? Yes or No

If you believe additional training is needed, please indicate what problems need to be addressed (circle all that apply):

- Basic communication skills (eye contact, rate of speech, excessive use of jargon, personal space)
- Professional attitude (sullen, not empathic, angry, giggles, other, please describe _____)
- Other: _____

NOTES



CHAPTER 19

Care during the Final Days of Life

“As a young military flight surgeon in the 60s and 70s, unfortunately, I spent almost six years as a POW of the Viet Cong...first in the jungles of Vietnam, and then in the notorious prisons of Hanoi. I had no medicine or instruments and could only palliate the dying prisoners, by simply holding them in my arms. Twelve died that way, 10 Americans, two West German nurses mistakenly captured. I hope that I was able to ease their suffering and help them to the other side.”

—F. Harold Kushner, MD, FACS
Surg Clin N Am 85 (2005) xi

Learning Objectives

Attitudes

- Reflect on the challenge of changing one's goals for a surgical patient from cure to comfort and a dignified death.
- Explore new definitions of “failure” and “success” related to the care of surgical patients who die.
- Reflect on past experiences in caring for dying patients.
- Clarify one's attitude toward physician-assisted death.
- Explore the differences in medical-surgical priorities versus patient and family priorities defining quality care at the end of life.

Knowledge

- Identify five common barriers to recognizing that a critically ill surgical patient is dying.
- List five common signs/symptoms of approaching death.
- Know how to assess a dying patient for distress.
- Define three general principles of symptom management in the last days and hours of life.
- Identify common symptoms experienced by patients in the final days of life.
- Understand the principle or rule of “double effect” in relation to relieving pain, dyspnea, and other symptoms at the end of life.
- Define the difference between palliative sedation and physician-assisted death.
- Define grief and bereavement.
- Know five common concerns among families of dying patients.

Skills

- Demonstrate appropriate use of drug and nondrug treatments to manage symptoms in the final days of life.
- Demonstrate compassion and competence in death pronouncement and autopsy request.
- Offer comfort and support to bereaved family and loved ones of the deceased person.

NOTES

Pre/Post Test

1. List three signs of approaching death:

- a. _____
- b. _____
- c. _____

2. What is the primary treatment for dyspnea in the last days of life?

3. What is physician-assisted suicide?

4. List two situations that require notification of the coroner at time of death:

- a. _____
- b. _____

5. Differentiate grief from bereavement:

Answers

(1) functional status decline, difficulty swallowing, mottled and cool extremities, (2) opioids, (3) a physician intentionally provides the means for a patient to take his or her life, (4) death in the operating room; accidental death, (5) **bereavement** refers to the *state of loss, grief* to the *reaction to loss*.

Teaching Outline

The Dying Surgical Patient— General Considerations

Surgeons rarely think of their patients as “dying.” The surgeon-patient relationship usually develops under circumstances and in contexts primarily associated with promotion of health and recovery, making recognition of imminent death difficult. Surgeons typically view death in two forms: as a perceived personal failure at the end of a long intensive care unit (ICU) stay following an operation with multiple complications or as an often unrecognized process in a patient experiencing the final stages of a terminal illness. To identify imminent death in their patients, surgeons must recognize the following:

- Denial of impending death is a defense mechanism, used not only by the dying patient, but sometimes also by the patient’s surgeon.
- Acceptance of the imminent death of a terminally ill patient is not therapeutic nihilism but is essential for providing optimal care.
- It is essential to reassess the status of critically ill patients frequently in the context of questions from family and clinical staff about outcome and prognosis.
 - The goals of care of patients (and families) may diverge from surgical goals.
 - A prolonged dying process may not be consistent with a patient’s goals of care.
- The natural history of an advanced illness (for example, metastatic cancer) in conjunction with poor performance status will likely define survival, regardless of the potential impact of any surgical intervention.
- Terminally ill patients who are imminently dying are very sick, and very sick people tend to seek care in emergency departments, which may lead to surgical consultation.
- Patients and families assume any operation is curative, unless explicitly told otherwise.

The Syndrome of Imminent Death

A number of changes in the physical and cognitive condition of terminally ill patients develop that herald the transition to the period of time referred to as “actively dying,” or the syndrome of imminent death. This period is measured in hours to days, depending on the underlying circumstances:

- Functional status declines: bed-bound and dependent for all activities of daily living (toileting, transfers, feeding, dressing, and bathing)
- Decreased desire for food or fluids; decreased urine output
- Increased sleep and/or a shift in sleep-wake cycle (altered circadian rhythm)
- Increased difficulty swallowing oral medications
- Increased difficulty clearing oropharyngeal secretions, leading to noisy upper airway sounds (“death rattle”)
- Vivid dreams and “hallucinations” (often encounters with deceased relatives)
- In severe cachexia, may be unable to keep eyes closed during sleep because of loss of retroorbital fat pad.
- May be more aware than appears: avoid referring to apparently comatose patients in the third person when in their presence
- Delirium
- Fecal and/or urinary incontinence
- Fever due to silent aspiration
- Changing respiratory pattern: fast, slow, periods of apnea or Cheyne-Stokes respiration
- Peripheral mottling and cooling of extremities (analogous to acrocyanosis in neonates)

NOTES

Common Family Concerns during the Final Days of Life

Attending to the care of a loved one who is dying is physically and emotionally challenging for family and other caregivers. Common questions that arise during this period include the following:

- Have we made the right decisions?
- Is he or she suffering?
- Can he or she hear me? What should I be saying?
- How will I know when death is close?
- What happens after the death?

Surgeons can help families by anticipating these questions, providing information about the typical progression of signs and symptoms of approaching death, and offering support through continuing presence and involvement up to and following the death.

Management of Common Signs and Symptoms in the Last Week of Life

The most common symptoms and signs in the last week of life include cognitive changes, respiratory changes with or without dyspnea, fever, noisy breathing, and pain. For families, agitated delirium, dyspnea, and pain are extremely distressing and deserve emergency attention. General principles of symptom management in the last days of life include the following:

- Provide counsel and support to families regarding the signs and symptoms of impending death.
- Anticipate symptoms before they develop.
- Minimize technological interventions (most symptoms can be managed with drugs and simple nondrug therapies).
- Plan for alternative drug delivery routes because the oral route may not be possible.

Dyspnea (air hunger):

- Assess for easily correctable problems (for example, kinked oxygen tube, fluid overload)
- Pulse oximetry not indicated during the last week of life
- The primary treatment is opioids
- Cautiously titrate opioid therapy to perceived comfort and reduction of respiratory rate to a range of 15 to 20 breaths per minute.
 - For opioid-naïve patients, typical starting doses of an immediate-release opioid for breathlessness are 10 mg oral morphine or 1 to 2 mg of IV/SQ morphine.
 - For patients already receiving opioids for pain, a 25 to 50 percent increment in the dose of the current immediate-release agent for breakthrough pain will often be effective in relieving breathlessness and breakthrough pain.
- An initial trial of nonpharmacologic therapy may be helpful.
 - Air movement across the face generated by a fan can be tried.
- Supplemental oxygen by nasal cannula (2–3 L/min) may bring some subjective relief. Oxygen via face mask or BiPap devices is generally not indicated and may increase agitation.
 - Humidify supplemental oxygen to avoid exacerbation of dry mouth.

Noisy respirations (death rattle)

- Caused by a collection of secretions in the upper airways that cannot be cleared by the dying patient; the patient is typically not conscious
 - Distress associated with the death rattle is primarily experienced by people attending to the dying patient, including loved ones and caregivers.
- Suctioning is generally not helpful and can cause distress to the patient.
- Reassure loved ones about the cause and patient's experience of the death rattle.
- Position patients on the side as much as possible to reduce pooling of secretions in the posterior pharynx.

NOTES

- Reduce or discontinue artificial hydration.
- Antisecretory drugs such as glycopyrrolate (0.2–0.4 mg IV/SC q 4–6 h), scopolamine, or atropine are used to reduce secretions.
 - Glycopyrrolate does not cross the blood-brain barrier and, thus, is less likely to cause confusion and amnesia that may be seen with scopolamine and other atropine-like agents.

Dry mouth

- Often interpreted as thirst, but in the dying patient, there is typically little relationship between the symptom of dry mouth and fluid status and the serum sodium level.
- Humidify any supplemental oxygen.
- Provide assiduous mouth care every 2 hours with a sponge moistened with patient's favorite carbonated beverage to keep mucous membranes moist.

Pain

- Often less of a problem in the last days of life; reduced activity level associated with lower incident pain
- As death approaches and patients become less verbal, pain assessment will rely on nonverbal signs of distress (for example, grimacing, increased respiratory rate). Be sure to ask families and caregivers whether they think the patient is suffering; they have important information to help guide the clinician.
- Opioids used to control pain before the phase of imminent death should be continued, even as patients gradually lose consciousness.
 - Do not stop opioids abruptly, even if the patient becomes nonresponsive; sudden withdrawal can cause opioid withdrawal and severe distress.
 - Lower renal clearance of opioids may result in greater potency or toxicity, especially myoclonus, which is an indication for dose reduction.
- Adequate dosing of opioid analgesics may require alternative route(s) of administration: transdermal, rectal, or parenteral (IV or SQ).

- Severe pain crises in the last days of life are rare, but when inadequately addressed, may cause great and lasting distress (complicated grief) for loved ones.
- A pain crisis requires frequent physician assessment and input for optimal management. When a parenteral opioid infusion is needed, use the SQ route for patients who have no IV access—PICC or central lines are rarely needed. For severe pain that is difficult to manage at home, offer to transfer the patient to an inpatient setting.

Cognitive Failure: Delirium

- Manifested in most patients with increasing somnolence and some degree of delirium, treating somnolence is not recommended; it is part of the dying process.
- Terminal delirium can be hypoactive or hyperactive:
 - Hypoactive:** gradually increasing somnolence accompanied by periods of disorientation and mild confusion; may respond to reassuring presence of loved ones and caregivers with minimal need for medications
 - Hyperactive:** a more distressing form of delirium, manifested by increasing agitation that best responds to major tranquilizers (for example, haloperidol, chlorpromazine, or any of the newer oral antipsychotics, risperidone and quetiapine). Minor tranquilizers (benzodiazepines) should generally be avoided because they paradoxically worsen delirium.
- Although opioids, especially a recent dose escalation, can worsen delirium, opioids should not be restricted if agitation is due to uncontrolled pain or breathlessness.
- Spiritual experiences (for example, vivid dreams, seeing deceased relatives) should not be confused with delirium.

NOTES

Emergencies at the End of Life

Other potential emergencies at the end of life include massive hemorrhage (for example, carotid “blowout” from neoplastic encasement and erosion) and severe respiratory distress with choking or asphyxiation (for example, from sudden airway collapse or rapid progression of respiratory failure). It is critically important to prepare the patient and family (caregivers) for this possibility with a sensitive discussion explaining what might occur and the measures that will be taken to ensure the patient’s comfort.

- For massive external hemorrhage, if possible, have dark-colored (maroon) heavy absorbent towels immediately available to soak up the blood and mitigate the horror for caregivers.
- For intense anxiety due to air hunger, initially give morphine, 10 mg IV/SC, in the hospital setting and 30 mg of concentrated morphine elixir SL in the home setting.
- For additional anxiolysis with massive bleeding or impending loss of airway, lorazepam or midazolam can be given.

Psychosocial and Spiritual Issues in the Last Days of Life: The “Work of the Dying”

The work of the dying is ultimately focused on addressing spiritual or existential issues that are manifested in the context of relationships. It is ideally the work of a lifetime, but, unfortunately for some people, it may have been ignored or neglected for most of life until the awareness of imminent death allows no further delay. Much of the work of the dying is focused in three major areas:

- *Meaning*: Why am I suffering?
- *Value*: Do I still have value to my family, my work, my community?
- *Relationship*: “Whom have I wronged?” “Who has wronged me?” (Sulmasy)

Excellent symptom control focused on maintaining effective cognition and comfort is essential to facilitate this process. In recognition of these needs, the surgeon should:

- Be more available for active listening at the bedside: maintain or even increase frequency of bedside visits.
- Be prepared to listen patiently and to compassionately answer repetitive questions from family and friends.
- Deemphasize the technical aspects of care (particularly in the ICU) in discussions with the patient and family and focus more on ensuring patient comfort.
- Encourage greater family presence and involvement in the dying patient’s care (for example, helping with mouth care).
- Be sensitive to protecting the dignity of an increasingly vulnerable, dependent patient.
- Be aware of the grieving process, not only of the family and friends, but also providers, including oneself.

NOTES

Withdrawal of Life-Sustaining Treatments for ICU Surgical Patients

For critically ill surgical patients, a shift in goals from cure and life prolongation to comfort until anticipated death can represent a real challenge in the busy, sometimes chaotic setting of a modern ICU. The ultimate goal is to establish a peaceful, supportive, and *quiet* environment for the dying patient and family. To achieve this goal, several actions can be taken:

STEP 1: DECISION AND DOCUMENTATION

1. The prognosis, options, and goals of care should be fully explored with the patient, legal surrogates, and/or family; consensus has been reached that removal of mechanical ventilation (RMV) with expected death is the optimal treatment course. The attending physician must be involved in this discussion. The patient's primary nurse, social worker, or chaplain should be included in this discussion unless the patient or family requests otherwise. Related issues to be discussed before RMV include the following:
 - Withdrawal of artificial hydration and feeding
 - Withdrawal of blood pressure support
 - Withdrawal of antibiotics and blood products
 - Withdrawal of ET tube after ventilator is discontinued
 - Wishes concerning organ donation

NOTE: There is no compelling ethical or medical rationale for continuing any of these treatments once a decision has been made to RMV.
2. The attending physician documents in the medical record the date and time of the RMV discussion, who was present, and the agreed-on goals and plan; a DNR order is written.
3. Plans are discussed with the family about the process of care if survival is expected for a prolonged period following RMV.

4. A time and date are established for RMV and other treatments.

STEP 2: PREPARATION FOR RMV

1. A senior physician should be available before, during, and immediately after RMV to supervise symptom control and provide counseling and support to family and staff. An order is written to discontinue the ventilator.
2. The primary nurse and physician will provide information to the patient or family:
 - Who can be present during the RMV process
 - Potential outcomes: rapid versus delayed death, potential symptoms and signs
 - Process of withdrawal: ventilator, ET tube, other tubes
3. Notify respiratory therapy of RMV timing; ask therapist to be present.
4. Ask family and/or surrogates if they want a chaplain or other clergy present before or during RMV.
5. Premedication for sedation: (Note: The primary goal of sedation is to prevent dyspnea after extubation; unintentional apnea following sedative administration may occur, but, in general, if all parties have agreed on the plan of care, a decision to continue with ventilator withdrawal is appropriate; reversing agents (eg, naloxone) should not be administered.
 - Discontinue paralytics and test for return of neuromuscular function.
 - Administer a bolus dose of morphine, 2 to 10 mg IV, and start a continuous morphine infusion at 50 percent of the bolus dose per hour (fentanyl or hydromorphone are acceptable alternatives).
 - Administer 1 to 2 mg of midazolam IV (or lorazepam). (Note: Sedation should also be administered to a comatose patient.)
 - Titrate medications to minimize anxiety and achieve the desired state of sedation before extubation.

NOTES

- Have additional medication (morphine and midazolam or lorazepam) drawn up and ready to administer at the bedside, if needed, to provide symptom relief.
 - If needed, other agents for sedation before and following extubation include pentobarbital and propofol.
6. If previously discussed and agreed to, discontinue blood pressure support medication, artificial hydration and feeding, and remove orogastric and/or nasogastric tubes.
 7. Remove restraints and unnecessary medical paraphernalia, including patient electronic monitoring devices, pulse oximetry, and so forth.

STEP 3: REMOVAL OF MECHANICAL VENTILATION

1. Ensure adequate sedation.
2. Prepare space at the bedside for family members.
3. Ask a respiratory therapist to silence all ventilator alarms; set FiO_2 to 21 percent, and remove PEEP. Observe for signs of respiratory distress; adjust medication.
4. In general, there is little rationale for maintaining an endotracheal tube following discontinuation of ventilator support:
 - Reduce IMV rate to 4 and/or pressure support to 6 during 5 to 15 minutes. Observe for signs of respiratory distress, and adjust medications to optimize patient comfort. Deflate endotracheal tube cuff, extubate, and suction (if necessary) once comfort is achieved. Remove ventilator from bedside.
 - If continued intubation is desired by family or physician, use a t-piece, remove the ventilator from bedside, and continue to suction as necessary. Adjust medications to alleviate respiratory distress.
5. Observe for signs of respiratory distress, and adjust medication.

Ethical Issues in the Last Days of Life

A variety of treatments in and outside the ICU setting might be forgone if they do not meet the patient's expressed goals of care or are not achieving suitable physiologic effect, such that they are prolonging the dying process rather than sustaining life. These treatments might include antibiotics for refractory infections, chemotherapy for advanced malignancies, dialysis, or artificial nutrition and hydration. In refusing these treatments, patients are neither committing suicide nor requesting death (see later text), rather they are recognizing that death cannot be impeded.

All surgeons must be prepared to discuss the appropriateness of treatments with patients and their families. Patients or their surrogates may choose to forgo operations that do not hold much promise of benefit or entail significant risks and burdens. One such area is transplant surgery. Patients facing redo transplants or failed allografts require honest discussions about the likelihood of additional organs becoming available and the success of subsequent transplants. It is incumbent on the surgeon to create realistic expectations so that the patient can hope for the best while preparing for the worst.

Major ethical issues at the end of life often reflect a tension between the Hippocratic principles of nonmaleficence ("do no harm") and beneficence (do a positive good for the patient) and the newer principle of patient autonomy or self-determination.

NOTES

The Doctrine of “Double Effect”

The doctrine of “double effect” means that a treatment (for example, opioid administration in a terminally ill patient) that is intended to help and not harm the patient (that is, relieve pain) is ethically acceptable even if a potential consequence (side effect) of its administration is to shorten the life of the patient (for example, by respiratory depression). The doctrine underscores the reality that sometimes treatments with potentially dangerous side effects must be used to relieve patient distress. There is a fundamental ethical difference between titrating medications rapidly to achieve relief of distress and administering a very large bolus with the intent of inducing apnea. Ultimately, the doctrine of double effect depends on the *intent* of the individual. *However, in the vast majority of cases, the rule need not be invoked because opioids can usually be safely titrated for symptom relief in advanced illness without significant risk of respiratory depression.*

Physician-Assisted Suicide (Death)

In physician-assisted suicide, a physician intentionally provides the means, while the patient is the direct, proximate cause of his or her own death (for example, the physician writes a prescription for a lethal dose of medication, but the patient takes the medication, or not, at the time of his or her choice).

- In euthanasia, the physician is the direct cause of the *intended* death of the patient (for example, physician administers a lethal dose of medication with the intention of causing death).
- Ethically, there is no fundamental moral difference between physician-assisted suicide and euthanasia.
- Intent is everything; one’s actual intent must be *documented*.
- Withholding or withdrawing treatments, which are no longer beneficial, is neither euthanasia nor assisted suicide.
- Providing opioids to treat pain or dyspnea, with the intent of symptom relief, is neither euthanasia nor assisted suicide.

The use of medication to induce unconsciousness, explicitly for the control of refractory physical symptoms, is termed *sedation for refractory symptoms* (also called palliative or terminal sedation). The use of this technique is considered ethically acceptable for selected refractory physical symptom control and does not represent euthanasia or assisted suicide. However, some advocate that there is little difference between physical symptoms (for example, pain) and psychological or spiritual suffering and, thus, recommend the same approach, of sedation to unconsciousness, for these cases. The use of sedation in this manner is considered far more controversial and should not be attempted without expert consultation from palliative medicine, psychiatry, and others skilled in managing psychospiritual distress.

Pronouncing Death

When called to pronounce a death, a surgeon should look for and document the following:

- Complete lack of responsiveness to verbal or tactile stimuli
- Absence of heart beat and respirations
- Fixed pupils

Other common findings after death include the following:

- Skin color change to a waxy hue as blood settles
- Gradual poikilothermia
- Sphincter relaxation with loss of urine and feces
- Eyes may not close, and jaw may fall open

For deaths in the hospital:

- Family (durable power of attorney for health care or next-of-kin) must be notified (in person, if possible).
- A coroner may be needed under specific circumstances (for example, deaths in the operating room, deaths resulting from an accident).
- The pronouncing physician needs to complete a death certificate according to local regulations.
- Survivors may be approached regarding potential autopsy and organ donation.

NOTES

- Assist families in accommodating religious rituals that may be important to the dying patient or the family; religious rituals may include special preparation of the body and specific prayers before the body is removed from the site of death.
- Adequate time should be allowed for farewells and grieving at the bedside.

For deaths in the home:

- The hospice nurse on call should be contacted immediately.
- Do not call 911 unless the patient made a prior request for a full resuscitative effort.
- In some states, deaths at home (without hospice enrollment) may require a brief police investigation and report.

Grief and Bereavement

Grief is a multifaceted response to loss that may include emotional (sadness), physical (appetite change), cognitive (memory disturbance), behavioral (change in daily routine), social (isolation from friends), and philosophical (why me?) dimensions. While the terms are often used interchangeably, *bereavement* refers to the *state of loss* and *grief* to the *reaction to loss*. Losses include physical function, employment, status, family role, a sense of safety and order, and loved ones. Our response to loss is varied; researchers have moved away from the conventional view that people move through an orderly and predictable series of responses to loss to one that considers the wide variety of responses that are influenced by personality, family, culture, and spiritual and religious beliefs and practices. The term *mourning* is synonymous with grief over the death of someone (I am in mourning). The word is also used to describe a complex of cultural behaviors (wearing black clothes), in which bereaved people participate or are expected to participate (adapted from Wikipedia). All people involved in the care of a patient experience some degree of grief and bereavement, including the family, other caregivers, the surgeon, and other members of the health care team. Without adequate opportunity to acknowledge the grief associated with the inevitable losses in a busy surgical practice, surgeons may be at risk for pathologic grief, often experienced as “burnout.”

Although grief and bereavement are accentuated in the immediate period around death, it is important to note that patients and families may begin the process of bereavement well before the time of death, as patients and families grieve incremental losses of independence, vitality, and control.

Bereavement takes time, and surgeons can fulfill an important role by giving “permission” to grieve (even before the death occurs) by describing the process and what grieving people might expect.

Bereavement Support

There are a variety of forms of bereavement support that can provide help to people who are grieving:

- Sending a condolence card
- Attending a patient’s funeral
- Participation in a periodic institutional memorial service

Additional forms of assistance to grieving family members include the following:

- Individual counseling
- Support groups; local hospitals and hospices often provide grief support groups.

NOTES

Bibliography

The EPEC-O Project: Educating Physicians in End-of-Life Care-Oncology Module 6: Last Hours of Living: National Cancer Institute; 2007.

Hinshaw DB. Spiritual issues in surgical palliative care. *Surg Clin North Am.* 2005;85(2):257–272.

Menkin E, Wolfson R. Fast Fact and Concept #022: Writing a Condolence Letter. 2nd ed. July 2005. End-of-Life Physician Education Resource Center. Available at: http://www.eperc.mcw.edu/fastFact/ff_022.htm. Accessed July 23, 2009.

Nelson KA, Walsh D, Behrens C, et al. The dying cancer patient. *Semin Oncol.* 2000;27(1):84–89.

Pawlik TM, Curley SA. Ethical issues in surgical palliative care: am I killing the patient by “letting him go”? *Surg Clin North Am.* 2005;85(2):273–286, vii.

Quill TE, Dresser R, Brock DW. The rule of double effect: a critique of its role in end-of-life decision making. *N Engl J Med.* 1997;337(24):1768–1771.

Rousseau P. Existential distress and palliative sedation. *Anesth Analg.* 2005;101(2):611–612.

Rubinfeld GCS. Principles and practice of withdrawing life-sustaining treatment in the ICU. In: Curtis JR, ed. *Managing Death in the Intensive Care Unit*. New York, NY: Oxford University Press; 2001.

Sulmasy DP. Spiritual issues in the care of dying patients: “... it’s okay between me and god.” *JAMA.* 2006;296(11):1385–1392.

Sulmasy DP, Pellegrino ED. The rule of double effect: clearing up the double talk. *Arch Intern Med.* 1999;159(6):545–550.

Sykes N, Thorns A. The use of opioids and sedatives at the end of life. *Lancet Oncol.* 2003;4(5):312–318.

Twycross R, Lichter I. The terminal phase. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine*. New York, NY: Oxford University Press; 1998:977–992.

Weissman D. Fast Fact and Concept #003: Syndrome of Imminent Death. 2nd ed. July 2005. End-of-Life Palliative Education Resource Center. Available at: http://www.eperc.mcw.edu/fastFact/ff_003.htm. Accessed July 23, 2009.

Weissman DE, Heidenreich CA. Fast Fact and Concept #004: Death Pronouncement. 2nd ed. July 2005. End-of-Life Palliative Education Resource Center. Available at: http://www.eperc.mcw.edu/fastFact/ff_004.htm. Accessed July 23, 2009.

Worden JW. Bereavement care. In: Berger AM, Portenoy RK, et al, eds. *Principles and Practice of Palliative Care and Supportive Oncology*. 2nd ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2002:813–818.

NOTES

Small Group Exercise

Postgraduate surgical trainees are at risk for burnout due to frequent inability to fully process (grieve) the deaths of their patients that they witness. This small group exercise is intended to give an opportunity to reflect on deaths witnessed. Each surgical resident will be asked in their small group (six or fewer participants) to relate examples of “good” and “bad” deaths witnessed. Each will then be asked to characterize the elements of the dying experience for patients that define the deaths as good or bad. These elements can be written on a flip chart and later shared in a larger, plenary group discussion, if desirable.

Some prompters to stimulate discussion regarding a good versus a bad death include the following:

- Was physical distress controlled in your patient?
- Were the spiritual needs of your dying patient and his or her family fully addressed?
- Was there conflict between the patient’s family and the surgical team?
- Was there conflict within the surgical team—between nurses and physicians or between surgical residents and the attending physician—about the patient’s perceived prognosis or goals of care?
- Was the patient’s dying process inappropriately prolonged?
- What is the most important feature of a good death?
- What may be the most defining characteristic of a bad death?
- Have you ever had the opportunity to attend a memorial service or funeral for one of your patients who died?
- How does having this discussion make you feel?
- Do you more often remember the good or bad deaths you have witnessed?
- Are there things you wish you could have done differently in the care of your dying patient?
- Have you ever felt like quitting surgery after the death of one of your patients?
- Have you ever experienced a sense of hope after witnessing a death of one of your patients?

At the end of the discussion, the instructor may then want to ask the participants:

- Was this a painful exercise?
- Did you find it helpful?
- How will you use this experience in the care you provide to your next dying patient?

NOTES

CHAPTER 20

Discussing Spiritual Issues— Maintaining Hope

“Who is there in all the world who listens to us? Here I am in my nakedness, with my wounds, my secret grief, my despair, my betrayal, my pain which I can’t express, my terror, my abandonment. Oh, listen to me for a day, an hour, a moment, lest I expire in my terrible wilderness, my lonely silence. Oh God, is there no one to listen?”

—Seneca

Learning Objectives

Attitudes

- Values the role of the surgeon and palliative care team in supporting a dying patient's exploration of spiritual and religious issues.
- Respects the spiritual beliefs of the patient and the patient's right to an independent spiritual search.

Knowledge

- Differentiates between spirituality and religion.
- Understands how unique elements of each patient's spirituality and religion can be integrated into decision making and treatment planning.
- Describes the nature and variety of hope experienced by patients with a terminal illness and how "hope" comes to mean more than "cure."
- Recognizes at least three patient statements that are spiritual in nature, and describes how to engage patients in spiritually meaningful ways.
- Distinguishes between appropriate and inappropriate roles for the surgeon regarding spirituality and religion.
- Describes the role of chaplain, social worker, and other allied health professionals in supporting patients with spiritual and religious concerns.

Skills

- Performs a spiritual assessment.
- Demonstrates how to reframe the concept of "hope" for dying patients.
- Collaborates with palliative care team members.
- Engages patients in a respectful discussion of their spirituality.
- Incorporates the patient's spirituality and religion into a written history and treatment plan.

NOTES

Pre/Post Test

1. Describe the difference between the terms *religion* and *spirituality*:

2. List two reasons why surgeons should address spiritual matters with their patients:

a.

b.

3. List three common spiritual questions that dying patients often pose to their surgeon:

a.

b.

c.

4. Describe two spiritual roles that are inappropriate for a surgeon to assume in relation to a patient:

a.

b.

Answers

(1) Religion is a culturally grounded set of beliefs around human experience. Spirituality is a broad concept of how each individual person views his or her relationship to the universe and/or a higher power. (2) Patients often want to discuss these matters with their physician. Illness leads most patients to ask spiritual questions. (3) *Why me? What is the point of continuing treatment? Was this all worth it?* (4) proselytizing; false representation as a spiritual/religious leader.

“Surgeons are technicians for whom the spirituality of death and dying process is terrifying.”

—T. Krizek (Spiritual dimensions of surgical palliative care)

Religion and Spirituality

Religion refers to a socially and culturally grounded system of beliefs concerning the cause, nature, and purpose of the universe and individual human life. Because religion is culturally and socially grounded, a person generally practices his or her religion within a defined religious community. Most of the world religions, including Christianity, Buddhism, Islam, Judaism, Hinduism, and Taoism, include five common elements described by Smith¹:

- **Explanation**—of life’s big questions. Where do we come from? Why are we here? Where do we go?
- **Tradition**—passing knowledge and practice from one generation to the next
- **Ritual**—gatherings of celebration and bereavement
- **Authority**—individuals recognized as religious advisors and counselors by virtue of talent, wisdom, study, or experience
- **Grace**—believing that in some sense “reality is on our side and can be counted on”¹

Each religion has specific practices that pertain to illness, healing, the dying process, death, and the period after death, which are rooted in the religion’s explanations, traditions, rituals, and authority. Individual patients may or may not ascribe to all of the practices and beliefs of their chosen religion.

Spirituality is a broader term than religion, referring to one’s personal understanding of the relationship between oneself as a human being—one’s spirit, one’s soul—other people, and the universe. Spirituality often encompasses one’s personal explanations of big questions—Where do I come from? Why am I here? Where do I go? What gives my life meaning? What is the meaning of my relationship with other people, and with the earth and universe? Is there meaning to my illness and suffering?

Sulmasy² describes the distinction between religion and spirituality in a similar manner: “Spirituality is about one’s relationship with the transcendent questions that confront one as a human being and how one relates to these questions. A religion, by contrast, is a set of texts, practices, and beliefs about the transcendent, shared by a particular community. Spirituality, in this respect, is broader than religion. While not everyone has a religion, spiritual issues, in this wider sense, arise for almost all dying persons.”

Why make a distinction between the spiritual and the religious? The distinction between the *spiritual* and the *religious* helps the physician and palliative care team understand and support the patient’s needs by reminding the care team to attend to the personal (spiritual) and social-cultural (religious) dimensions of an individual patient’s sacred experience. For some patients, spirituality is experienced within the context of an organized religion. Some patients do not practice a religion and yet have spiritual beliefs and practices.

NOTES

Why Address Spiritual and Religious Issues?

1. Understanding a patient's spiritual and religious beliefs helps the physician understand the whole person.
2. A majority of patients want their physicians to ask about spiritual and religious issues, to make referrals to appropriate sources of religious and spiritual support, and to incorporate the patient's spiritual and religious concerns into the plan of care, as appropriate.
3. Patients and families may have specific preferences regarding the treatment plan and the dying process that are rooted in their spiritual and religious beliefs and practices. These preferences may include specific needs related to religious rituals and traditions.
4. Dying patients often confront fundamental spiritual questions—Why did this happen to me? Has my life been worthwhile? What value do I have now? What happens after I die? For what may I hope? Why do I suffer? The patient may look to the surgeon “at the bedside” for support. When a surgeon stands with a patient facing death, the surgeon inevitably supports the patient's inquiry into these fundamental questions. The surgeon can affirm the worth of the patient, encourage the patient to express his or her concerns and questions, and connect the patient to other people such as chaplain and family members.
5. Spiritual pain may cause physical symptoms, particularly pain.
6. Addressing spiritual and religious issues may increase the surgeon's awareness of how his or her own belief system and experience of the sacred may influence his or her interactions with patients and families.
7. Integration of spiritual and religious dimensions is considered a standard of care (for example, Davidson et al³).

Surgeon's Role in Spiritual and Religious Issues

Appropriate Roles for the Surgeon

The surgeon's role in the spiritual care of patients is grounded in the spiritual dimensions of the physician-patient relationship, including the fact that the surgeon will be present with patients as they encounter some of the most profound moments of their life. The physician:

- sees and treats the whole person, not merely a disease;
- responds to the patient with compassion;
- affirms the patient's unique worth and dignity; and
- stands by the patient who is facing suffering and death.

Two appropriate and important roles for the surgeon in facilitating the patient's spiritual and religious coping are *catalyst* and *guide*.

1. Catalyst

When the surgeon assesses spiritual and religious issues, this inquiry acts as a catalyst for the patient and family to explore spiritual and religious questions that have meaning at this time in their lives. The surgeon's inquiry and resulting dialogue may encourage the patient and family to keep sacred space open for exploration. Thus, the surgeon encourages and supports the patient's personal discovery and dialogue with family, friends, chaplain, and religious teachers.

NOTES

2. Guide

Once spiritual and religious issues have been assessed, the surgeon serves a guide to:

- make sure that the health care team integrates spiritual and religious issues into the plan of care and
- encourage the patient to obtain support from his or her own social network.

The surgeon does not need extensive knowledge about the patient’s religion or spirituality. Instead, the surgeon’s role is to support patients in finding resources to address their spiritual and religious concerns. Recognition of spiritual needs during serious illness for appropriate triage and referral is analogous to recognizing the need for neurosurgical consultation for management of an acute epidural hemorrhage.

Inappropriate Roles for the Surgeon

As the surgeon explores the patient’s experience of the sacred, there is potential to assume an inappropriate or an unethical role with the patient. Two inappropriate and unethical roles are the following:

1. Spiritual or religious teacher or leader
Surgeons can encounter ethical difficulties if they assume the role of spiritual advisor, teacher, or leader. This role assumption creates a dual relationship between the physician and patient (physician-patient and teacher-seeker). There will inevitably be conflicts between these roles that compromise the physician’s ability to provide medical care for the patient.
2. Proselytizing to convert the patient to the physician’s religious beliefs

The physician should not attempt to convert a patient to the physician’s religious perspective. Maintaining appropriate boundaries in the physician-patient relationship may be particularly challenging when the patient is struggling with fundamental spiritual and religious questions.

Four Tasks for Incorporating Spirituality and Religion into the Care of Patients

Assessing a patient’s spiritual and religious beliefs and then incorporating these into care may seem like a daunting task. However, integrating the patient’s spiritual and religious beliefs and practices into the plan of care is an accepted standard in palliative care. This goal can be achieved by accomplishing four manageable tasks.

TASK 1: Take a spiritual history to assess spiritual and religious issues.

There are various guides for physicians in taking a spiritual history. Maugans⁴ spiritual history is perhaps the most comprehensive and practical approach.

- SPIRIT, Maugans⁴
- FICA Spiritual History, Puchalski and Romer⁵
- HOPE, Anandarajah and Hight⁶
- Existentially Focused History, Okon⁷

Maugans⁴ spiritual history (SPIRIT) is perhaps the most comprehensive and practical approach. S-P-I-R-I-T indicates: (S) spiritual belief system, (P) personal spirituality, (I) integration with a spiritual community, (R) ritualized practices and restrictions, (I) implications for medical care, (T) terminal events planning.

TASK 2: Communicate the spiritual history to the treatment team, document the spiritual history in the record, and incorporate the spiritual history into treatment planning.

- Document the spiritual history appropriately and respectfully in the patient’s record.
- With guidance from the patient, and based on the spiritual history, incorporate specific activities and outcomes into the interdisciplinary treatment plan for the patient.
- Do not assume that the patient and family ascribe to specific religious beliefs and practices of the religion they belong to; confirm beliefs and practices with the patient and family.

NOTES

TASK 3: Continue a dialogue regarding spiritual and religious issues. Foster realistic hope, and affirm the worth and value of the person.

- Spiritual support occurs in the context of a meaningful human relationship in which patients can feel accepted, valued, and respected. Continue to invest in fostering this relationship, and continue to engage the patient on issues related to spirituality.
- Take time to sit with your patient, practice active listening, and appropriate touch.
- Continue to nurture your relationship with the patient with honesty, availability, active listening, and reassurance.
- Learn the patient's language of meaning as you take the spiritual history and return to important themes.
- Follow-up on the treatment plan, and revise as needed.
- Engage the entire treatment team, and ask the patient whether he or she wants to consult with clergy or other religious advisors.
- Ask if the patient has encountered any barriers to the practice of his or her spiritual or religious life.

TASK 4: Recognize common spiritual dilemmas.

Patients may express feelings and thoughts that evoke one or more of the following themes involving the past (guilt, painful memories), the present (isolation, anger, unfairness), or the future (fear, hopelessness). Common verbal expressions include the following:

- Unfairness—*Why me?*
- Unworthiness—*I don't want to be a burden.*
- Hopelessness—*What's the point?*
- Guilt and punishment—*My disease is a punishment. But I have led a good life.*
- Isolation and anger—*No one understands me.*
- Confusion—*Why is this happening to me?*
- Vulnerability—*I am afraid.*
- Abandonment—*My God (or my family) doesn't care about me.*

When you hear these themes, reflective listening and normalizing can highlight the dilemma in a manner that helps the patient recognize the issue and accept his or her feelings. For example:

Patient: *Sometimes I feel like I'm being punished*

Surgeon (reflective listening): *You feel like you are being punished.*

Patient: *Yes, I do.*

Surgeon: *Tell me more about that.*

Patient: Describes feelings in more detail.

Surgeon (normalizing): *Many patients whom I have worked with have had similar feelings. Is there someone you trust that you can discuss these feelings with?*

Highlighting, recognizing, and affirming emotions in this manner often guide patients toward healing. For some patients, a brief discussion with their surgeon will be sufficient. For others, this type of discussion with their surgeon will prompt them to further discuss their feelings with friends, family, or a spiritual or religious advisor. When the surgeon sees that a patient continues to struggle with an issue, the surgeon will want to refer to a more qualified individual to address ongoing psychological or spiritual issues. The surgeon should note, however, that some psychologists and clerics may, themselves, be uneasy with or inexperienced at counseling in end-of-life situations. These discussions can trigger strong emotions and reactions on the part of the surgeon, as well. When this occurs, the surgeon can also benefit by seeking out spiritual reassurance and counsel, particularly surrounding the time of a death.

NOTES

Maintaining Hope

Maintaining hope in the face of terminal illness is one of the great challenges facing people near the end of life. Most dying patients want and need honesty from their physicians regarding their disease and prognosis. Sometimes health care providers fear that in the face of terminal illness, honesty is cruel because it will force the patient to lose hope. However, one may be honest with patients and still maintain hope through a change in focus, away from hopes that are long-term, to hopes that are short-term or spiritual. Maintaining hope through realistic short-term goals is extremely important for patients and families. The potential for healing begins with a redefinition of hope. *Hope* has been defined in the context of terminal illness as the positive expectation for meaning attached to life events. Hope lies in meaning that is attached to life, not in events themselves. It is a loss of meaning and a loss of hope that often underlie requests for physician-assisted suicide.

Some strategies for beginning a dialogue about short- and long-term goals include the following:

1. Ask the patient, “*Do you have long-term hopes and dreams that have been threatened by this illness?*” Identifying loss is the first step in grieving. Support the patient in recognizing and grieving the possible loss of these hopes:
 - Validate and recognize feelings of anger, sadness, and denial.
 - Encourage the patient to talk with others about this loss, especially if these hopes and dream included others.
2. Ask the person if there are upcoming events they want to participate in—a wedding, birth, trip, and so on.
3. Encourage the patient to make short-, medium-, and long-range goals with an understanding that the course of terminal illness is always unpredictable.
 - To attend a family gathering (dinner, wedding, birth)
 - To walk again
 - To feel better tomorrow
 - To be at home
 - To visit with close family or friends
 - To be remembered
 - To have a future beyond physical existence

NOTES

References

1. Smith H. *The Illustrated World's Religions: A Guide to Our Wisdom Traditions*. New York, NY: HarperCollins; 1994.
2. Sulmasy DP. Spiritual issues in the care of dying patients: "it's okay between me and God." *JAMA*. 2006;296(11):1385–1390.
3. Davidson JE, Powers K, Hedayat KM, et al; American College of Critical Care Medicine; Society for Critical Care Medicine. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005. *Crit Care Med*. 2007;35(2):605–622.
4. Maugans TA. The SPIRITual history. *Arch Fam Med*. 1996;5(1):11–16.
5. Puchalski CM, Romer AL. Taking a spiritual history allows clinicians to understand patients more fully. *J Palliat Med*. 2000;3(1):129–137.
6. Anandarajah G, Hight E. Spirituality and medical practice: using the HOPE questions as a practical tool for spiritual assessment. *Am Fam Physician*. 2001;63(1):81–89.
7. Okon TR. Palliative care review: spiritual, religious, and existential aspects of palliative care. *J Palliat Med*. 2005;8(2):392–414.

Bibliography

- Brody H. Hope. *JAMA*. 1981;246(13):1411–1412.
- Daaleman TP, Nease DE Jr. Patient attitudes regarding physician inquiry into spiritual and religious issues. *J Fam Pract*. 1994;39(6):564–568.
- Hinshaw D. The spiritual needs of the dying patient. *J Am Coll Surg*. 2002;195(4):565–568.
- Koenig BA, Gates-Williams J. Understanding cultural difference in caring for dying patients. *West J Med*. 1995;163(3):244–249.
- Krizek T. Spiritual dimensions of surgical palliative care. *Surg Oncol Clin N Am*. 2001;10(1):39–55.
- Kuhn CC. A spiritual inventory of the medically ill patient. *Psychiatr Med*. 1988;6(2):87–100.
- Levin JS, Larson DB. Religion and spirituality in medicine: research and education. *JAMA*. 1997;278(9):792–793.
- Lo B, Ruston D, Kates LW, et al. Discussing religious and spiritual issues at the end of life: a practical guide for physicians. *JAMA*. 2002;287(6):749–753.
- Matthews DA, McCullough ME, Larson DB, et al. Religious commitment and health status: a review of research and implications for family medicine. *Arch Fam Med*. 1998;7(2):118–124.
- Millspaugh CD. Assessment and response to spiritual pain, part 1. *J Palliat Med*. 2006;8(5):919–923.
- O'Connell LJ. Religious dimensions of dying and death. *West J Med*. 1995;163(3):231–234.
- Parker-Oliver D. Redefining hope for the terminally ill. *Am J Hosp Palliat Care*. 2002;19(2):115–120.
- Puchalski CM, Larson DB. Developing curricula in spirituality and medicine. *Acad Med*. 1998;73(9):970–974.
- Spiritual Pain. Kaye P, ed. *Notes on Symptom Control*. Essex, CT: Hospice Education Institute; 1990:261–267.
- Thomason CL, Brody H. Inclusive spirituality. *J Fam Pract*. 1999;48(2):96–97.

Teaching Workshop | Faculty Guide

1. Ask participants to generate examples of patients for whom religion and spirituality have been important resources. Ask them to identify patients for whom the health care team has responded effectively to incorporate religious and spiritual issues into the treatment plan. Ask them to also identify patients for whom the health care team was not as effective as one would hope.
2. Review the outline.
3. Divide the group into pairs, and ask each pair to practice taking a spiritual history with the other person using the **Spiritual History and Documentation Outlines** as a guide. After about five or 10 minutes, prompt the pairs to switch roles.
4. Ask each person to work by himself or herself and write a brief spiritual history chart note summarizing the history just obtained. Use the outline provided.
5. In a large group, ask for feedback on the interview. How did it go? What challenges do they anticipate incorporating this into their interview? Does anyone have a particular way of asking a question to share with the group?
6. Homework: Ask each participant to practice taking and documenting a spiritual history on three inpatients or outpatients. Staff these histories with a palliative care faculty member.

Spiritual History Documentation—Outline

S—spiritual belief system

P—personal spirituality

I—integration with a spiritual community

R—ritualized practices and restrictions

I—implications for medical care

T—terminal events planning

NOTES



INDEX



A

Acetaminophen, 22, 23, 24, 30, 151
Actiq. *See* **Fentanyl**
Acute confusional state. *See* **Delirium**
Addiction, 24, 28, 30, 35, 36.
See also **Psychological dependence**
Adjuvant analgesics. *See*
Analgesics, subentry Adjuvant
Alcohol, 28
Allegra. *See* **Fexofenadine**
Allergy, 24
Alvimopan, 89
Ambien. *See* **Zolpidem**
Amitriptyline, 25, 39
Amphetamines, 28
Amitriptyline, 126
Analgesics. *See also* **Specific drug names and Opioids**
 Adjuvant, 25, 151, 154
 Anticonvulsants/antiepileptics, 25, 154
 Antidepressants, 25, 154
 Corticosteroids, 25
 Local anesthetics, 25
 Rescue, 152
Anger, 5, 6, 8
Anhedonia, 67, 68, 72
Anorexia. *See* **Wasting syndromes**
Antiandrogenic agents and Depression, 68
Anticholinergic agents, 48, 57
Anticonvulsants/antiepileptics, 25, 125, 126, 154
Antidepressants, 25, 69, 70, 126, 127
 Tricyclic, 25, 154
Antiemetics, 78
Antihistamines, 30, 78, 125
Antipsychotics, 59, 126
Anxiety, 5, 12, 29, 48, 69, 70
 in **Children**, 155-156
Anxiolytics, 48, 50
Anzemet. *See* **Dolasetron**
Appetite, 109
 Stimulants, 109
Appetitant, 79
Artificial hydration and nutrition.
See **Nutrition, subentry Artificial**
Asthenia. *See* **Wasting syndromes**
Aspirin, 22
Atarax. *See* **hydroxyzine**

Ativan. *See* **Lorazepam**
Autonomy, 135, 137, 169, 172, 236
Avinza. *See* **Morphine**
Awareness (by physician)
 Environmental, 6, 7
 of Others, 6, 234
 of Patients, 7, 8
 Personal, 1-16, 47, 68, 72, 185
 Strategies, 12

B

Baclofen, 126
Bad news, delivering, 179-190
Documentation, 185
 Participants, 183
 in Pediatrics, 156
 Setting, 183
 Steps, 183
 by Telephone, 185
Balance, personal and professional, 9
Barbiturates, 48, 57, 68
Benadryl. *See* **Diphenhydramine**
Benzodiazepines, 28, 30, 48, 57, 59, 61, 68, 69, 78, 79, 127
Bereavement. *See* **Grief and bereavement**
Beta-blockers and Depression, 68
Bethanechol, 89, 153
Bisacodyl, 88, 90
Boundaries, with patients, 6
Bowel
 Function, 87
 Obstruction, malignant, 93-104
 Differential diagnosis, 97
 Epidemiology and pathogenesis, 97
 Management, 98, 101-103
 Mechanisms, 97
 Prognosis, 97
 Symptoms and signs, 97
 Stimulants, 88, 155
 Transit time, 89
Burnout, 5
 Prevention, 9, 10, 12
 Risk factors, 10
 Signs and symptoms, 3

C

Cachexia. *See* **Wasting syndromes**
Caffeine, 110
CAM. *See* **Confusion Assessment Method**
Camphor/menthol, 125
Capsaicin cream, 125
Carbamazepine, 25, 154
Casanthranol, 88
Cascara, 88
Case studies. *See* **Guides**
Castor oil, 88
Celexa. *See* **Citalopram**
Cephulac. *See* **Lactulose**
Cerebral cortex, 77
Chemoreceptor trigger zone, 77
Chlorpromazine, 48, 59, 79, 126
Cholestyramine, 125, 129
Chronulac. *See* **Lactulose**
Citalopram, 71
Cocaine, 28
Codeine, 22, 30
Colace. *See* **Docusate**
Combination drug products.
See **Opioids, subentry Opioid-nonopioid combinations**
Communication, 8, 30, 48, 50, 69, 119
 of Bad news, 156, 179-190
 Cultural differences, 170-171
 Interaction patterns, personal, 8
 Malignant bowel obstruction, 99
 about Palliative surgery, 136, 139
 in Pediatrics, 156
 Request for nondisclosure, 172
 Spiritual issues, 248-249
Compazine. *See* **Prochlorperazine**
Conflict, 6, 9, 69
 Managing, 197, 208
Confusion, 24
Confusion Assessment Method, 58
Conscious sedation, in children, 151
Constipation, 24, 68, 84-92, 97, 153, 155
 Acute, 87
 Chronic, 87
 Differential diagnosis, 88, 92
 Management, 88-90
 Prophylaxis, 90
 Symptoms, 87

Consultation, 30, 31, 118, 119, 183, 195, 197, 208, 217, 237, 248

Malignant bowel obstruction, 99
Psychiatric, 68, 69

Control, behavior and lifestyle

Over drug use, 28
Over schedule, 10
Over time, 10
Over work environment, 5, 10

Corticosteroids. *See Steroids*

Cough suppressants, 48

CRIS scale (Crying, Required oxygen, Increased vital signs, Expression, and Sleeplessness), 150

Culture and cultural issues, 6, 28, 30, 118, 119, 162-178

Bias and prejudice, 168
Conflict management, 197
Cultural competency vs literacy, 167
Explanatory Model, 169, 175-176
Relationships, imposed, 168
Resources, 173
Rituals, 168, 238
Values and meaning, 168

Cunniff-Dixon Foundation, vii

D

Death and dying, 5, 6, 15, 37, 50, 67, 68, 231-240

Cultural beliefs and practices, 169-171
Discussion worksheet, 13
Emergencies, 234
Family concerns, 232
at Home, 238
Pronouncing death, 237-238
Requirements for coroner, 237
Request for nondisclosure, 172
Symptom management, 232-233
Syndrome of imminent death, 231
Withdrawal of treatments, 235-236
Work of the dying, 234

Decision making

Capacity of patients, 69, 118, 119, 195, 207
Cultural differences, 169, 170, 197, 198
Malignant bowel obstruction, 99
Patient involvement in treatment plan, 30, 36, 117, 207, 208

in Pediatrics, 147, 156, 160-161

Delirium, 24, 48, 53, 57, 58, 59, 61, 68, 70, 71, 110, 153, 233

Agitated, 57, 233
Assessment, 57
Differential diagnosis, 57
Hyperactive, 57, 233
Hypoactive, 57, 68, 233
Treatment, 59

Dementia, 7, 57, 58, 61, 68, 69, 88, 117, 119

Demerol. *See Meperidine*

Demoralization, 9, 68, 72

Dependence, physical. *See Physical dependence*

Dependence, psychological. *See Psychological dependence*

Depression, 5, 9, 12, 23, 29, 35, 36, 57, 63, 67, 68, 69, 70, 72

Assessment, 68
Diagnostic criteria, 67
Differential diagnosis, 68
Major, 70
Respiratory. *See Respiratory depression*
Risk factors, 67
Treatment, 69

Desyrel. *See Trazodone*

Dexamethasone, 25, 48, 79, 98

Dextroamphetamine, 110

Dextromethorphan, 48

Diazepam, 48, 59, 126

Dilaudid. *See Hydromorphone*

Diphenhydramine, 79, 127, 153

Discharge planning, 31

Disease vs illness, 7

DNAR (do not attempt resuscitation). *See DNR*

DNR, 137, 197, 203-212
Cultural meanings, 170
Discussions, 207-208
Conflict management, 208
Documentation, 208
Participants, 207
Setting, 207
Statements to avoid, 208

Docusate, 89, 155

Dolasetron, 79

Do not attempt resuscitation. *See DNR*

Do not resuscitate. *See DNR*

Dopamine, 78

Dopamine antagonists, 126

Dose escalation, 22, 24, 25, 37, 151

Double effect, of drugs, 50, 237

Dronabinol, 79, 110

Drugs and drug therapy. *See also*

Specific drug names and classifications

as Cause of delirium, 59
Constipation, 88-90
Duration of action, 23, 30
Dyspnea, 47, 50, 232
Hiccups, 126
Insomnia, 127
Nausea and vomiting, 78
Pain. *See Pain*
Potency ratios, 23
PRN orders, 24
Pruritis, 125
Route of administration, 24, 34, 151
Tolerance, 23, 24, 28, 35, 36, 37
Toxic effects, 24

Dry mouth, 233

Dulcolax. *See Bisacodyl*

Duloxetine, 25

Dyspnea, 43-52, 59, 68, 232

Differential diagnosis, 47
Drug therapy. *See Drug therapy, Dyspnea*

E

Edinburgh Depression Scale, 68

Emend. *See Aprepitant*

EMLA, 151

End-of-life care, 227-240

Enemas and suppositories, 89

Equianalgesic doses, 23, 24, 34

Ethical considerations, 48, 118, 135, 136, 139, 147, 236-237

Double effect, of drugs, 50, 237
Request for nondisclosure, 172

Euthanasia, 37, 48, 50, 68, 237

Intent of medication administration, 50, 237
vs Symptom control, 50, 237

Expectations

in FIFE, 7

Explanatory Model, of culture, 169, 175-176

F

Faces Pain Scale, 150

Faculty guides. *See* **Guides**

Family conferences and counseling, 101, 119, 156, 191-212

- Documentation, 198
- Ten-step process, 195-198

Fatigue, 68, 69, 70, 72, 153.
See also **Wasting syndromes**

Fear of using drug therapy, 50

Fecal impaction, 90

Feelings

- in FIFE, 7

Fentanyl, 23, 24, 34, 37, 39

Fentora. *See* **Fentanyl**

Fexofenadine, 125

FIFE (Feelings, Ideas, Function, Expectations), 7

FLACC (Face, Legs, Activity, Cry, and Consolability) Pain Assessment Tool, 150

Function

- in FIFE, 7

G

Gabapentin, 25, 39, 125, 154

Glucocorticoids, 78, 79

Glycopyrrolate, 48, 98

Goals of care, xi, 22, 59, 61, 101, 119, 136, 139, 145, 146, 148, 160, 191-202, 207, 208, 217, 231, 235, 236-237

- Cultural issues, 170-171

GoLYTELY. *See* **Polyethylene glycol 3350**

Granisetron, 79

Grief and bereavement, 5, 6, 68, 69, 72, 217, 238

- Anticipatory, 67, 68, 69, 72
- Grief vs bereavement, 238

Guides

- Artificial nutrition and hydration, 120
- Bad news, delivering, 187-189
- Cachexia, anorexia, asthenia, and fatigue (wasting syndromes), 111
- Constipation, 92
- Cross-cultural encounters, 174-177
- Delirium, 61
- Depression, 72
- DNR discussion, 210-211

Dyspnea, 50-51

End-of-life care, 240

Goals of care and family conferences, 200-201

Hiccups, 129, 130

Insomnia, 129, 130

Malignant bowel obstruction, 101-103

Nausea, 81

Pain assessment and management, 32-42

Palliative care and hospice, 223-224

Palliative surgery, 139

Pediatrics, 159-161

Personal awareness and self-care, 12-15

Pruritis, 129

Spiritual issues and maintaining hope, 252

H

Haldol. *See* **Haloperidol**

Haloperidol, 59, 61, 79, 98

Heroin, 28

Hiccups, 126

- Assessment, 126
- Differential diagnosis, 126
- Treatment, 126

Hope, 101, 241-254

- Maintaining, 250

Hospice, 99, 101, 197, 213-226

- Care issues, 220
- Cultural meanings, 170
- Eligibility for services, 218
- Prognostic indicators, 220
- Heart failure, 221
- Liver failure, 221
- Model for End-stage Liver Disease (MELD) score, 221
- Palliative Prognostic Scale, 221

Medicare benefit, 219

Misconceptions, 147

Payment sources, 219

Providers, 218

Reimbursement, 217, 219

Services provided, 218

Settings, 218

Hospital Anxiety and Depression Scale, 68

Hydration, 99, 101, 114-120

Hydrocodone, 22

Hydrocortisone cream, 125

Hydromorphone, 23, 24, 34, 36

Hydroxyzine, 30, 79, 125, 153

I

Ibuprofen, 22

Ideas

- in FIFE, 7

Insomnia, 67, 69, 70

- Assessment, 127
- Differential diagnosis, 127
- Treatment, 127

Interaction patterns, personal, 8

Interferon

- and Depression, 68

Interpreters, 168

Interventional radiology for malignant bowel obstruction, 98

Inventory

- Personal and professional goals, 14

K

Kadian. *See* **Morphine**

Ketamine, 25

Ketorolac, 98

Kytril. *See* **Granisetron**

L

Lactulose, 155

Language, 168

Laxatives, 78, 88-90. *See also* **Specific drug names**

- Powder Pudding, 89

Learner assessment forms

- Delivering bad news, 190
- DNR discussion, 212
- Goals of care and family conferences, 202
- Pain assessment, 42
- Palliative care and hospice, 225

Legal issues, 37, 118, 119, 135, 139, 147

- Double effect, of drugs, 50, 237

Level of consciousness, 37, 57

Levorphanol, 23, 37

Lidocaine, 25, 48, 151, 154

Lifestyle, 9

Lioresal. *See* Baclofen

Local anesthetics, 25

Lorazepam, 30, 48, 59,
61, 71, 79, 127, 155

M

Marinol. *See* Dronabinol

Medicare hospice benefit, 219

Medications. *See* Drugs

Megace. *See* Megestrol

Megestrol, 110

MELD score. *See* Model for End-
Stage Liver Disease score

Meperidine, 23, 30, 36, 152

Methadone, 23, 24, 34, 37, 154

Methylnaltrexone, 89

Methylphenidate, 70, 110, 126

Metoclopramide, 78, 79, 89, 126, 155

Midazolam, 48, 59

Midbrain intracranial
pressure receptors, 77

Mindful practice, 6

Mini-Mental State
Examination, 58, 61, 68

MiraLAX. *See* Polyethylene glycol 3350

Mirtazapine, 69, 71, 72

MMSE. *See* Mini-Mental
State Examination

Modafinil, 110

Model for End-stage Liver
Disease score, 221

Morphine, 23, 24, 30, 34,
36, 37, 39, 47, 61, 151

Dose equivalents, 23

Muscle relaxants, 126

Myoclonus, 24, 153

N

Naloxone, 37, 89, 153

Naproxen, 22

Narcan. *See* Naloxone

Nausea and vomiting, 24,
68, 69, 73-83, 97

in Children, 155

Differential diagnosis, 77

Meanings of “nausea,” 81

Mechanism, 77

Neostigmine, 89

Neuroleptics, 59, 70

Neurontin. *See* Gabapentin

Neurotoxicity, 24

Noncurative surgery, 135

Nondrug therapy, 39

Delirium, 59

Dyspnea, 47, 50

Hiccups, 126

Insomnia, 127

Nausea and vomiting, 78

Pain, 25, 30

Pediatrics, 149

Pruritis, 125

Nonsteroidal antiinflammatory
drugs, 30, 39, 154

NSAIDs. *See* Nonsteroidal
antiinflammatory drugs

Nutrition, 99. *See also* Hydration

Appetite, 109

Artificial, 114-120, 197

Benefits and burdens, 117

Withholding in children, 148

Total parenteral, 99, 101

O

Octreotide, 89, 98

Olanzapine, 59

Ondansetron, 79, 155

Opioid contract, 31

Opioid rotation, 153

Opioid tolerance, 23

Dosing guide, 23

Opioids, 12, 23, 24, 28, 30, 31, 34,
35, 36, 37, 47, 48, 50, 57, 59, 61,
68, 70, 98, 151, 154, 155, 233

Opioid-nonopioid combination
products, 22, 24, 30, 152

Overdosing

Pain medication, 23

Over-the-counter drugs, 22

Oxycodone, 22, 23, 24, 30, 34

Oxymorphone, 23

P

Pain, 7, 12, 17-42, 50, 57, 59,
61, 67, 68, 69, 97, 233, 247

vs Addiction, 35

Assessment, 22, 30

in Children, 150

Associated with psychological
factors, 29

Bone, 154

Breakthrough, 23, 24, 39, 151

Management, 18, 22, 23, 31,
35, 37, 38. *See also* Specific
drug names and Opioids

in Children, 149-154

in Substance use and abuse, 30, 35

Reluctant clinicians, 36

Provider fears, 35

Mild, 22

Mixed, 39

Moderate, 22

Neuropathic, 22, 25, 39, 154

Perception by children, 149
and Psychiatric disorders, 28

“Real,” 35

Severe, 23

Somatic, 22, 39, 154

Total, 150

Undertreated, 28

Visceral, 22, 154

Palliative care, 5, 213-221

Barriers, 5

of Children. *See* Pediatric care

End of life, 227-240

Gap between palliative
care recommendations and
actual practice, 12

Humanizing, 5

Interdisciplinary, 217

Principles, v, 217

Providers, 217

Reimbursement, 217, 219

Surgery. *See* Surgery, *subentry* Palliative

Palliative Prognostic Scale, 221

Panic, 29, 48

Patient Health Questionnaire, 68

Pediatric care, 141-162

vs Adult care, 147

Assessment, 146

DNR, 148

Do not intubate (DNI), 148
 Goals, 145, 148
 Hospice, 147
 Hydration, 148
 Interdisciplinary care, 148
 Nonpain symptoms, 155-156
 Nutrition, 148
 Pain management. *See also* Pain
 Analgesic dosing
 Methods (by ladder, clock, mouth, and child), 151
 Neonates, 150, 152
 Premature infants, 152
 Rescue dosing, 152
 Parental involvement in care, 149
 Symptom management, 149-156
Pemoline, 110
Pentobarbital, 48
Percocet. *See* **Acetaminophen; Oxycodone**
Pharmacotherapy. *See* **Drugs and drug therapy**
Phenergan. *See* **Promethazine**
Phenobarbital, 48
Phenolphthalein, 88
Phenytoin, 25, 126
Physical dependence, 24, 28, 35, 36
Physician-patient relationship, 169-170
 Boundaries, 6
Placebos, 30
Polyethylene glycol 3350, 89, 90, 155
Potency ratios, 23
Powder Pudding (laxative), 89
Pre/post tests, 4, 21, 46, 56, 66, 76, 86, 96, 108, 116, 124, 134, 144, 166, 178, 182, 194, 206, 216, 230, 245
Prednisone, 25, 48
Pregabalin, 25
PRN orders for pain medication, 24
Prochlorperazine, 79, 81
Prolonged QT interval, 24
Promethazine, 79
Propoxyphene, 22, 152
Pruritus, 24
 Assessment, 125
 Differential diagnosis, 125
 Treatment, 125, 153
Pseudoaddiction, 24, 28, 30, 36
Psychiatric disorders, 29

and Pain, 28
 Factitious disorder, 29
 Hypochondriasis, 29
 Malingering, 29
 Management, 30
 Psychiatric comorbidity, 29
 Somatization disorder, 29

Psychogenic pain. *See* **Pain, associated with psychological factors**

Psychological dependence, 24, 28, 35, 36

Q

Quality of life, xi, 22, 24, 67, 99, 117, 135, 136, 137, 138, 145, 148, 195, 196, 217

Questran. *See* **Cholestyramine**

Quetiapine, 59

R

Ranitidine, 155

Real pain. *See* **Pain, subentry "Real"**

Recommendations, from physicians, 118, 119, 136, 196

Reglan. *See* **Metoclopramide**

Reimbursement for palliative and hospice care, 217, 219

Religion

 Beliefs, 6, 50, 119, 171
 Physician role, 247-248
 Practices and rituals, 168, 169, 171, 238, 247
 vs Spirituality, 246

Remeron. *See* **Mirtazapine**

 Request for nondisclosure, 172

Resources

 Clinical, 7
 Cultural issues, 173
 for Families with sick and dying children, 157
 for Practitioners caring for sick and dying children, 157
 for Residents and trainees, 12
 Resident support group, 12

Respiratory depression, 24, 37

 in Children, 152, 153

 Death, 37

 Management, 37

Restoril. *See* **Temazepam**

Risperdal. *See* **Risperidone**

Risperidone, 59

Ritalin. *See* **Methylphenidate**

S

Scopolamine, 48, 79, 155

Sedation, 24

Sedatives, 48

Seizures, 24

Selective serotonin reuptake inhibitors, 25, 70-71, 72

Self-acceptance, 8

Self-care, surgeons, 1-16

 Pathways to, 9

 Strategies, 12

Self-knowledge. *See* **Awareness, subentry Personal**

Self-reflection, 3, 8, 12, 15

 Strategies, 15

Senna, 88, 155

Seroquel. *See* **Quetiapine**

Serotonin antagonists, 78, 79

Serotonin-norepinephrine reuptake inhibitors, 25

Sertraline, 71

Sleeping agents, 71

Somatoform disorder. *See* **Pain, associated with psychological factors**

Sonata. *See* **Zaleplon**

Spiritual care and challenges, 5, 6, 30, 69, 118, 146, 233, 171, 242-254. *See also* **Religion**

 Dilemmas, 249

 Spiritual history (of patients), 248

SSRIs. *See* **Selective serotonin reuptake inhibitors**

Steroids, 39, 48, 57, 70, 72, 110, 125, 154, 155

Stimulants, 69, 70

Substance abuse and use, 5, 9, 28, 30, 31, 35, 36, 69

 Assessment, 28

 Discharge planning, 31

Substance use disorder. *See* **Psychological dependence**

 Criteria, 28, 36

Sucralfate, 155

Sucrose, for pain management, 151

Suicide

 Assisted, 38, 48, 50, 68, 69

and Depression, 67

Risk, 68, 69

Sundowning, 61

Suppositories and enemas, 89

Surfak. *See* **Docusate**

Surgery

for Bowel obstruction,
malignant, 98, 101

Noncurative, 135

Palliative, 131-140, 217

Assessment, 136

Complications, 138

Palliative Surgery

Outcome Score, 138

Principles, 136, 217

Procedure

Selection, 136

Supportive, 137

Symptom relief, 137

Symptom control vs euthanasia.

See **Euthanasia**

Syndrome of imminent death, 231

T

Teaching workshops. *See* **Guides**

Temazepam, 127

Thiethylperazine, 79

Thorazine. *See* **Chlorpromazine**

Tolerance. *See* **Drugs**, *subentry* **Tolerance**

Torecan. *See* **Thiethylperazine**

Total parenteral nutrition.

See **Nutrition**, *subentry* **Total
parenteral nutrition**

Tramadol, 22

Transdermal fentanyl. *See* **Fentanyl**

Translators, 168

Trazodone, 69, 71, 127

Treatment goals. *See* **Goals of care**

True pain, *See* **Pain**, *subentry* "Real"

Trust, 169

Tyrosine kinase inhibitors

and Depression, 68

U

Underdosing

Pain medication, 23

Urinary retention, 153

V

Valium. *See* **Diazepam**

Valproic acid, 25

Values, 6, 7

Venlafaxine, 25

Versed. *See* **Midazolam**

Vestibular system, 77

Vistaril. *See* **Hydroxyzine**

Vomiting. *See* **Nausea and vomiting**

W

Wasting syndromes, 105-113

Causes, 109

Differential diagnosis, 109

Treatment, 110

Withdrawal of treatments, 235-236

Work of the dying, 234

Z

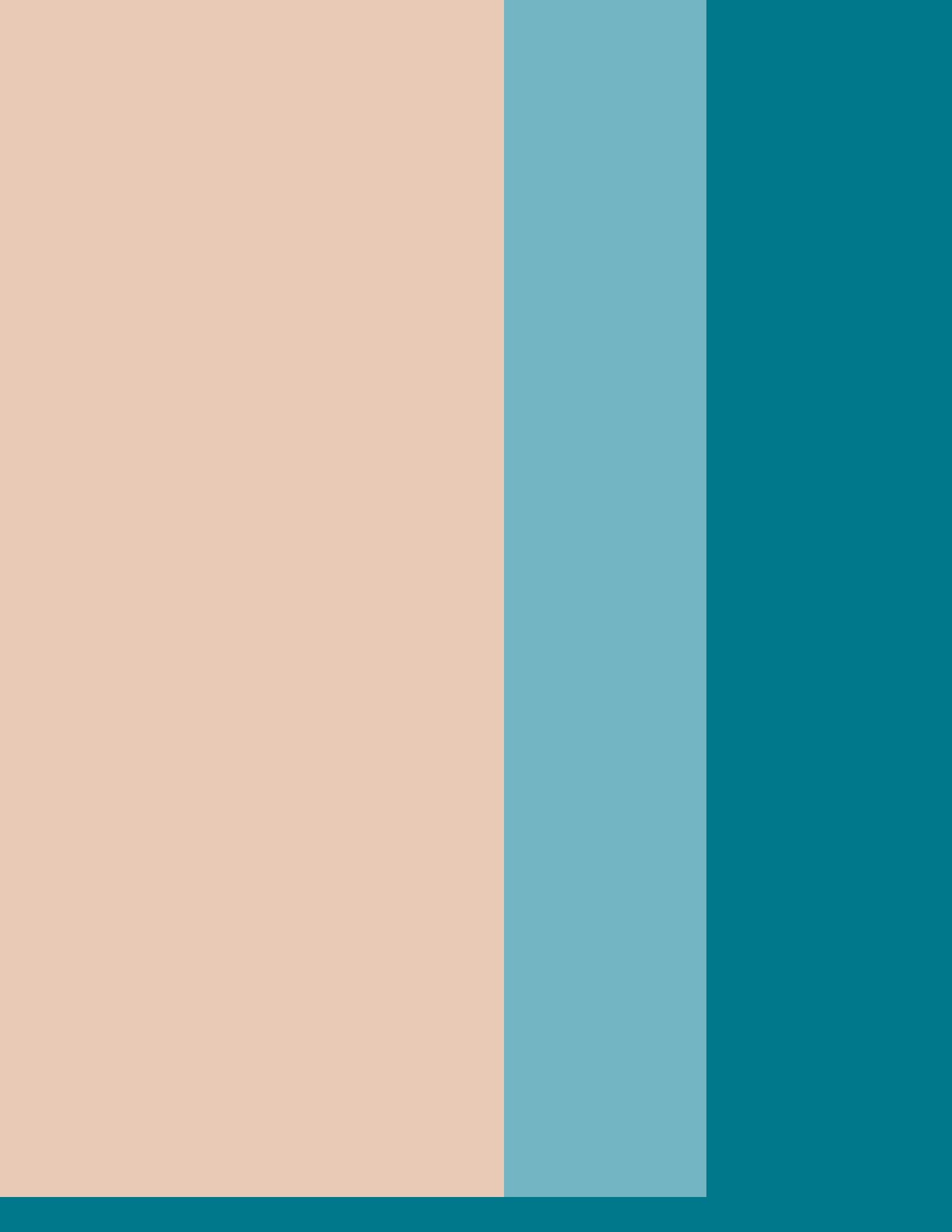
Zantac. *See* **Ranitidine**

Zofran. *See* **Ondansetron**

Zoloft. *See* **Sertraline**

Zolpidem, 71, 127

Zyprexa. *See* **Olanzapine**





CUNIFF DIXON FOUNDATION

PO Box 800
Essex, CT 06426
www.cunnifdixon.org



AMERICAN COLLEGE OF SURGEONS

633 N. Saint Clair St.
Chicago, IL 60611-3211
www.facs.org