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## Nursing Care at the End of Life: What Every Clinician Should Know

Susan E. Lowey  
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# **Nursing Care at the End of Life**



# **Nursing Care at the End of Life**

What Every Clinician Should Know

**Susan E. Lowey**

**Open SUNY Textbooks**

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## **About the Author**

Dr. Susan E. Lowey, PhD, RN, CHPN is an Assistant Professor in the Department of Nursing at the College at Brockport – State University of New York. Dr. Lowey works with both juniors and seniors in the traditional Nursing program, teaching Community Health Nursing and Nursing Research. She earned her PhD in Health Practice Research from the University of Rochester and was awarded a Claire M. Fagin Fellowship from the Building Academic Geriatric Nursing Capacity Program for her post-doctoral work. Improving care at the end of life, with a particular focus on symptom management, is the focus of Dr. Lowey's research. The majority of her clinical practice has been as a community health hospice nurse providing care for dying patients and their loved ones. Dr. Lowey holds national certification as a board certified hospice and palliative care nurse (CHPN) through the National Board for Certification of Hospice and Palliative Nurses. In addition, she is a certified ELNEC (End-of-Life Nursing Education Consortium) trainer (Core and Geriatric). She is also an appointed member of the National Board for Certification of Hospice and Palliative Nurses Registered Nurse Examination Development Committee and holds another appointment as the ESPO Representative on the Membership Executive Committee through the Gerontological Society of America. Dr. Lowey also serves as one of the faculty representatives for Omicron Beta, Brockport's Chapter of Sigma Theta Tau International Honor Society.

## About the Book

*Nursing Care at the End of Life: What Every Clinician Should Know* should be an essential component of the basic educational preparation for the professional registered nurse student. Recent studies show that only one in four nurses feel confident in caring for dying patients and their families and less than 2% of overall content in nursing textbooks is related to end-of-life care. Despite the tremendous growth in palliative and end-of-life care programs across the country, very few nursing education programs provide adequate education on this topic for future nurses. The purpose of this textbook is to provide an in-depth look at death and dying in this country including the vital role of the nurse in assisting patients and families along the journey towards the end of life. There is an emphasis throughout the book on the simple, yet understated value of effective interpersonal communication between the patient and clinician. The text provides a basic foundation of death and dying, including a brief historical examination of some main conceptual models associated with how patients cope with impending loss. An overview of illness trajectories and models of care, such as hospice and palliative care, are discussed. Lastly, the latest evidence based approaches for pain and symptom management, ethical concerns, cultural considerations, care at the time of death, and grief/bereavement are examined. The goal of this text is to foster the necessary skills for nurses to provide compassionate care to individuals who are nearing the end of life and families who are or have experienced the loss of a loved one. Every chapter contains a “What You Should Know” section which highlights and reinforces the main message nurses should know when caring for their patient.

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To date, the project has published 11 open textbooks. More information can be found at <http://textbooks.opensuny.org>.



# Introduction

Nurses and other health care clinicians can work in a variety of settings caring for many different populations of people. Some of these settings provide inpatient care to patients, such as hospitals or nursing homes, while others focus on outpatient type care, such as home health care. Nurses care for diverse populations of patients, both in age and in position along the health/illness continuum. One of the main goals in nursing care is to promote health and prevent illness. This is a goal for all our patients of any age. We care for both healthy and unhealthy newborns, children, adults, and older adults and provide interventions that are aimed at maintaining wellness and restoring health. The human body is remarkable and can heal from many serious conditions, including severe trauma, infectious diseases, and many other alterations in health. Sometimes, however, people develop conditions that cannot be cured despite the many modern advances in medicine. The end result of medicine that cannot reverse the process of illness eventually will be death. Sometimes death is unexpected, as from an accident, while other times it can be anticipated, as when chemotherapy is no longer effective for a person diagnosed with an advanced form of cancer. The majority of these deaths will occur in a healthcare setting, which is where most nurses work. Nurses working in healthcare settings not only provide care to people who are restoring their health, but also to those who are dying. It is essential that nurses and other clinicians have the knowledge and skills to care for patients who are dying and their families who are dealing with impending loss.

In the Institute of Medicine (IOM) report, *Approaching Death: Improving Care at the End of Life* (1997), the consensus of committee members is that every healthcare professional who will care for dying patients and families' needs to have a basic educational preparation in order to be able to provide both competent and compassionate care. Although national efforts such as the development of End of Life Nursing Education Consortium (ELNEC) have increased the number of nurses and nurse faculty trained in end-of-life care, there continues to be a lack of preparedness in end-of-life care competency among nurses. Previous research has found only one in four nurses feel confident in caring for dying patients and their families, and that less than 2% of overall content in nursing textbooks were related to end-of-life care (Kirchoff, Beckstrand, Anumandla, 2011; Ferrell, Virani, & Grant, 1999). Despite the tremendous growth in palliative and end-of-life care programs across the country, very few nursing education programs provide adequate education on this topic for our future nurses. Most end-of-life care content is scattered throughout nursing programs, if at all, and there usually is no specific course or textbook that focuses on the subject. Although only a small percentage of nurses practice in the specialty of palliative care and hospice, all nurses should have educational preparation in end-of-life care because of the widespread contact nurses have with people at the end of life.

Perhaps the greatest message this book hopes to bring to students learning a healthcare profession is about the power of your voice. This is one area in which you don't need to have a 4.0 grade point average to make a difference in the life of your patient. Yet, practicing effective communication with patients is often the least practiced skill during nursing school. More of an emphasis is often placed on honing in on other more technical skills such as administration of injections, sterile technique, or insertion of a urinary catheter. While acquiring competence and confidence in all the aforementioned skills is essential during nursing school, so is acquiring competence and confidence in effective communication skills. This is a vital part of the role of any professional health care clinician when communicating to patients, families, and other members of the healthcare team. If one doesn't possess confidence in their basic communication skills with patients on routine matters, than other more difficult kinds of communication encounters, such as with persons who are actively dying or with families who have just lost a loved one, will be the upmost challenge. Yes, nurses will continue to provide competent care in the "technical skills" associated with nursing; however, they will often overlook and refrain from engaging in the type of communication which this book is dedicated to fostering.

It is especially vital to patients and families going through this process to be able to have healthcare professionals who they can have open communication with. The goal of this book is to introduce students to the reality that interactions will happen with patients that are uncomfortable. Being a nurse or other healthcare professional does not exclude us from having difficult or uncomfortable conversations with people. These will occur and it is important to be prepared for it. What would you do or say when you walk into a room to give your patient their scheduled medication and they say to you, "So did you hear, I only have 2 weeks left" or "I am done with that awful chemo, I want to go home and die." Your natural inclination might be to ignore what you heard, administer the medication, and quickly leave the room. In my 20+ years in healthcare, I have witnessed this outcome more times that I can count. Nurses do not avoid these conversations because they are not knowledgeable, or because they do not care. In fact, they care very much and do not know how to respond in a way that they perceive is helpful to the patient. They do not want to say the wrong thing. At the end of life, however, saying nothing is the wrong thing. Chapters 10 and 12 of this book will go in depth as to how to respond to patients and families during these difficult times in their lives.

This textbook is divided into three parts: Anticipation, In the Moment, and Afterwards. Each section is meant to depict a temporal period of time that patients and families go through during the end of life. The chapters in Anticipation discuss topics that introduce death and dying, including historical perspectives, trajectories of illnesses leading to the end of life, types of care at the end of life, and initiating discussions about end-of-life care with people with serious illnesses. The second part, In the Moment, explores the management of various concerns related to people at the end of life, including pain, symptoms, and dis-

ness. Care at the time of death is discussed, as this is the last phase of life and it is especially important to be able to provide excellent nursing care to patients and families during this time. Finally, *Afterwards* is the third and final part of this book; topics include ways nurses can help families find closure and deal with their grief. The final chapter in this part is written to promote self-reflection among nursing and healthcare students regarding death and dying.

Lastly, if you are a student reading this introduction, please know that you are taking an important first step in acquiring the competence and fostering the compassion you will need to provide quality care to patients and families in need. Most nursing students go into the profession because they want to make a difference in the lives of people in need. Many want to be a part of restoring a person's health or being able to contribute to saving a life. Few enter the profession specifically to provide comfort to patients who are dying, yet most nurses will encounter that situation many times throughout their career. This book, along with your education and training throughout nursing school, will give you the foundation to be able to recognize and respond to patients and families who are dealing with the end of life. In time, you will gain confidence and experience, both of which are essential for providing optimal care to patients who are dying. In the meantime though, as a novice nurse, you must remember that although you might not feel like you have all the right answers to comfort a dying patient or grieving family, you have more than you think. It is never wrong to simply say, "I'm sorry, I wish this wasn't happening to you" or to quietly sit with someone and hold their hand. Your presence, if you are truly "present," will be comfort enough.

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**PART I**

# **Anticipation**



# 1

## A Historical Overview of End-of-Life Care

“

History cannot give us a program for the future, but it can give us a fuller understanding of ourselves, and of our common humanity, so that we can better face the future.

-Robert Penn Warren

### Learning Objectives

- Describe how death and dying has changed in this country over the past few centuries.
- Identify the current top ten causes of death in the United States.
- Explain what end-of-life care is and what it encompasses.
- Identify the role of the nurse in end-of-life care.

Death, especially in the United States, is a topic that makes people uncomfortable. Physical death is the cessation of all vital functions of the body, including heartbeat and respiration. Some religions believe that it is the end point of life here on earth. As such, death is often an event that is both dreaded and perceived negatively. People do not like to talk about it, plan for it, or acknowledge it, even when it is present. Death can be a normal event that occurs in the daily work setting for those who work in healthcare. Nurses care for patients who have illnesses or injuries that can cause or contribute to their death. Depending on the specific work setting of the nurse, their exposure to patient deaths will vary. Most nurses, however, will routinely encounter patients who are dying or have died and families who are dealing with that loss.

### Historical Trends in Death & Dying

In the twenty-first century, the way that death is perceived by both the layperson and medical professional, greatly differs from the way death was perceived in the past. This is because there have been many changes regarding death and dying in this country over the last century. In the 1800s, little could be done for the sick outside of easing symptoms. Deaths usually occurred suddenly, often only days from the onset of illness. Infectious and communicable diseases such as smallpox, diphtheria and cholera were the predominant cause of death. The average life expectancy was around 50 years of age (Stanhope & Lancaster, 2014). Back then, most deaths occurred in the home and most of the care that was provided came from family members rather than health care providers. So, in essence, death was quicker, people died in a familiar environment, and there seemingly were less or no choices available to save the person's life. If a person became afflicted with one of those infectious diseases, they would die.

Following the Civil War, nursing as a profession began to evolve. After the war, there was an increase in the building of hospitals, which in turn led to the development of formal training programs in nursing. The increase of hospitals as places that housed the sick changed the dynamic of both nursing care and how people died in America. Nurses, who previously cared for the sick at home, now worked in the hospital. Less people were dying at home with the increased growth and development of hospitals (Weatherford, 2010).

During the 1900s, the focus of medicine began to shift from only being able to provide comfort measures to curing the underlying disease. Significant advancements in medicine, education, and technology occurred during this century and this affected the way that death was viewed. Previously, becoming afflicted with an infectious disease meant certain death, but with the development of antibiotics and immunizations, people were now able to become cured from many of these diseases. People were living longer and infant mortality rates were decreasing, both of which are fairly good indicators of the health of a nation (Stanhope & Lancaster, 2014). Fewer people were dying at home and being cared for solely by their family. Familial care was superseded by a shift to care provided by professional health care workers. It was also during this century that the main causes of death (i.e., infection and communicable diseases) were eventually replaced by more chronic illnesses such as heart disease and stroke.

### Current Trends in Death & Dying

Over the past few recent decades, deaths have predominantly resulted from conditions related to the heart and cancer. According to the Centers for Disease Control and Prevention (2011), the leading causes of death (in order of prevalence) in the United States were as follows:

- Heart disease (596,577)
- Cancer (576,691)

- Chronic lower respiratory diseases (142,943)
- Stroke (cerebrovascular diseases) (128,932)
- Accidents (unintentional injuries) (126,438)
- Alzheimer's disease (84,974)
- Diabetes (73,831)
- Influenza and pneumonia (53,826)
- Nephritis, nephrotic syndrome, and nephrosis (45,591)
- Intentional self-harm (suicide) (39,518)

With a plethora of medical advances, many of these illnesses can be managed to increase both quantity and quality of life. The average life expectancy for persons in the United States is 77.5 years of age. People are often kept alive much longer than what would be expected with the natural course of the disease. The natural history of disease is defined as the course or progression of a disease process from time of onset to resolution (Stanhope & Lancaster, 2014). For example, a person diagnosed with stage 2 breast cancer can have a very good outcome with the current available treatments used to manage the disease. If left untreated, stage 2 breast cancer would eventually progress to stages 3 and 4, and ultimately contribute to the individual's death. Medicine has intervened in the natural history of disease, which has helped to save and lengthen the lives of many people. Unfortunately, this has also contributed to the inability or difficulty in knowing when to stop aiming for a cure. Even with the best medical care, the natural course of disease will progress and eventually lead to death. Often, medical treatments are continued beyond a point of providing tangible benefit to the patient and instead contribute to an increased burden. We will discuss more about weighing the benefits and burdens of treatment in Chapter 5. Despite all of the advances in medicine, the difficulty lies with determining an appropriate time to stop intervening in the natural course of illness.

### Improving the Quality of Care in Death & Dying

In the current decade, much attention has focused on improving the quality of death and dying in this country. There were two landmark projects that both shed light on areas that needed improvement. In 1995, The SUPPORT (The Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment) study was a groundbreaking \$29 million multi-year project that exposed the flaws associated with end-of-life care in this country. Some of the inadequacies SUPPORT found were related to the lack of communication about prognosis, patient's preferences and goals for care, and about death and dying in general. Physicians didn't mention death to their patients, and patients didn't ask; yet it was found that patients did want better information in order to be able to plan and to have their wishes fulfilled. A few years later, the Institute of Medicine produced a report entitled "*Approaching Death in America: Improving Care at the End of Life*" (1997). The report was written by a panel of 12 experts from medicine and nursing who specialized in caring for seriously ill patients. Some of the major issues that were found included finding better evaluation methods for measuring outcomes in end-of-life care, barriers to quality end-of-

life care, and improvements in providers' knowledge in providing appropriate care at the end of life. Following these projects, there was an increased value placed on improving the quality of end-of-life care in this country, as well as an increase in grant funds,

### End-of-Life Care

What is end-of-life care? End-of-life care is specialized care provided to a person who is nearing or at the end of life. Although you can find various definitions of this topic, there is no real consensus on when the period of time known as the end of life begins. Although it ends with the death of a person, when does it really begin and how can that be determined? That is one of the main barriers associated with providing quality end-of-life care because some people are afflicted with illnesses in which the exact end of life period is not as clear. We will discuss more about the various illness trajectories in the next chapter, but for now, we will focus on introducing this topic and its importance to nursing practice.

So it is understood that the end of life (EOL) period ends in death. For some people, the EOL period will be shorter. Perhaps they suffered acute trauma in an automobile accident and the end of life period was only a few hours or days in length. Sometimes the end of life period can be several years, as in persons afflicted with Alzheimer's disease. Either way, the EOL is a time in which specialized medical care is needed in order to ease suffering and improve the quality of life for whatever time an individual has left. The end of life is often the period in which treatments and procedures focus on comfort rather than having the primary goal of curing the underlying disease. Usually by the time a person is said to be at the EOL, death in the near future is somewhat anticipated, and therefore the goals of medical care tend to shift to a more comfort oriented model.

The perspectives and preferences of people about care at the end of life have been studied broadly. Patients with serious illness who know they were dying have reported many important elements of end-of-life care (Steinhauser, Christakis, Clipp, McNeilly, McIntyre, & Tulsky, 2000). Avoiding unnecessary life support, good communication and trust in their physician, continuity of care, and "completion of life" were common themes identified in another study of hospitalized patients with serious illness (Heyland, Dodek, Rocker, Groll, Gafni, & Pichora, et al., 2006). Symptom management, dignity and control, quality of life, and preparation were identified by people receiving palliative care services in another study (Aspinal, Hughes, Dunckley, & Addington-Hall, 2006). Previous research studies have found symptom and health care management, treatment preferences, and decision making at the end of life to be considered important among people who were dying.

The management of physical and psychosocial symptoms of people living with life-threatening illness has also been the focus of research studies, particularly reports of their inadequacy. The SUPPORT study examined many facets of the quality of dying in this country suggesting the need for a great deal of improvement in the care of the dying, particularly with pain and symptom management (The SUPPORT Principal Investigators,

1995). McCarthy, Phillips, Zhong, Drews, & Lynn (2000) found that over 25% of cancer patients experience serious pain during the last 3 to 6 months of life, with over 40% of these patients in significant pain during their last 3 days of life. In a systematic review of 44 studies, pain, fatigue, weakness, loss of appetite, and lack of energy were identified to occur in over 50% of patients with incurable cancer (Teunissen, Wesker, Kruitwagen, De Haes, Voest, & De Graeff, 2007). The concerns about inadequate symptom management have also been studied broadly in the literature in patients with cancer (Booth, Clemons, Dranitsaris, Joy, Young, & Callaghan, et al., 2007). Additionally, psychological components of advanced illnesses such as anxiety, depression, stress, coping, and terminal restlessness have also been explored in patients with cancer (DeFaye, Wilson, Chater, Viola, & Hall, 2006). Although much of the early work in end-of-life care was focused on the concerns and needs of patients with cancer, this has broadened to include patients afflicted with other end-stage illnesses such as heart failure, stroke, chronic pulmonary diseases, renal disease, progressive musculoskeletal disorders, and dementia and Alzheimer's disease.

The preferred place of death has been one facet of decision-making in people with terminal illnesses. Tang (2003) examined the preferred site of death in 180 patients with cancer and found 87% indicating a preference to die at home. Seventy-three percent of this sample regarded dying at their desired location highly important. Despite the preference to die at home, Gruneir, Mor, Weitzen, Truchil, Teno, & Roy (2007) found 53% of deaths from terminal illness occur at the hospital. Future projections for site of death suggest fewer than 1 in 10 people are expected to die at home by the year 2030 (Gomes & Higginson, 2008). In general, the literature suggests that people who know that they are dying prefer to die at home. Several studies have explored this topic with older persons and found that home might not be the preferred place of death for everyone. One study found the majority of older adults had strong feelings about not wanting to be a burden on their family by dying at home (Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004). Some other concerns from the older adult population pertained to their beliefs that quality care could not be given in the home setting and that having formal caregivers come into the home, would itself make care feel like it was not really "at home". Although hospice was the mode of care elderly people preferred if they were told their illness had no chance of recovery, the older group in this sample (>75 years) preferred receiving this type of care in an inpatient setting, such as a hospital or inpatient hospice (Catt, Blanchard, Addington-Hall, Zis, Blizard, & King, 2005).

### Role of the Nurse in End-of-life care

The nurse is a vital part of any healthcare encounter and is an important member of the healthcare team. Often, it is the nurse who has the most interaction with patients, and as a result can establish a good nurse-patient relationship. Although the actual tasks and role expectations may differ between nurses who specialize in end-of-life care, such as hospice or palliative care, and nurses in other practice areas, there are a few commonalities associ-

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ated with the role of any nurse taking care of patients at the end of life. This includes arming oneself with the knowledge required to provide care to patients who are living with a serious illness or injury. A nurse cannot provide adequate end-of-life care if he/she does not understand what end-of-life care entails. So in addition to the specialized knowledge, skills, and experience a nurse will acquire in a specialized unit or setting, each nurse must also have a basic understanding of the principles of end-of-life care. Training during a formal nursing program will introduce the topic but the nurse must be proactive in staying abreast of the current evidence base in the practice setting. Often there are educational in-service training sessions, lunchtime seminars, or various workshops that are offered in the workplace or community. These are ideal experiences that should be utilized to supplement and increase nursing expertise in caring for dying patients and their families.

Once the nurse has acquired this basic preparation, they should begin to think about the three areas that are important to patients who are at the end of life. These include comfort, information, and acceptance. All are equally important, although a large portion of end-of-life care training relies on providing adequate symptom management. The nurse's role includes the knowledge and skills to be able to maximize the patient's comfort level to their desired outcome. The nurse must think about comfort holistically to include not only physical and psychological comfort, but spiritual and social comfort as well. The only way to ensure adequate comfort in all these areas is to talk with the patient. The nurse must get to know the patient and establish a good nurse-patient relationship. A nurse can learn a lot about what is important to their patient by simply asking them.

In addition to being physically and emotionally comfortable, the patient will want information. This could be information about a medication or treatment, information about when they can expect to get test results, or information about what to expect as their illness progresses. While there are certain things that are not warranted in a nurse's role to talk about, such as delivering bad news or a terminal prognosis, there are plenty of other informative things that can be discussed with the patient. These are well within the scope of nursing practice and involve teaching and educating patient about their disease process, interventions, and outcomes. Patients who are facing the end of life have many things that they are dealing with that might be new or unusual and they need to be able to obtain answers for their questions. The nurse caring for them should be able to provide these answers. Again, if a nurse is asked a question that they do not know the answer to, they should tell the patient honestly that they do not know, but will find the answer and get back to them.

Lastly, patients who are dying need acceptance. Acceptance does not mean that the patient needs to be accepted personally by the nurse, but the patient needs to have acceptance in their lives. Acceptance could mean that they come to terms with their terminal illness or that they mend a broken relationship with someone they love. Their nurse, through a good nurse-patient relationship, should have a general understanding about their needs and help them to achieve their goals and address their concerns as their advocate.

### What You Should Know

- Chronic diseases replaced infectious diseases as the main causes of death after the turn of the 20th century
- Instead of being cared for by family and dying at home as in the past, most people in this country die in an institution.
- End-of-life care refers to specialized care provided to a person who is nearing or at the end of life, although there are no formal criteria as to when it should ideally begin.

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## Types and Variability within Illness Trajectories

“

The trouble with always trying to preserve the health of the body is that it is so difficult to do without destroying the health of the mind.

-G.K. Chesterton

### Learning Objectives

- Define illness trajectory.
- Identify the four most common illness trajectories.
- Describe the relationship of illness trajectories to hospice care.
- Explain the importance understanding patterns of illness for individual patients.

Most nurses learn about the term “illness trajectory” at some point during their nursing program. In loose terms, trajectory means “course,” and therefore illness trajectory means “course of illness.” By understanding which type of illness trajectory a patient has, it will help to provide answers for two important and common questions many patients have: “How long do I have?” and “What will happen?” (Murray, Kendall, Boyd, & Sheikh, 2005). Understanding the usual course of illness includes both the expected time frame until death and also what the patient can expect will happen with the illness’ progression. Often the length of time is less important for patients than what will happen during their upcoming days. In order for patients to prepare, many want to know what the end of life will be like. Although each patient’s illness and subsequent death can differ, you will see patterns in those final days of life. The illness trajectory largely determines these commonalities. Although not everyone will fit into a specific illness trajectory prognosis, trajectories help

both patient and nurse plan for the care needs of the patient. It is far better for the patient to know about, and be prepared for, what might happen.

In the late 1960s, two researchers by the names of Glaser and Strauss (Glaser & Strauss, 1968) wrote about three different trajectories that people who are dying experience. These include: surprise deaths, expected deaths, and entry-reentry deaths. Surprise deaths are those that are unexpected and usually happen without prior warning, such as a motor vehicle accident. Expected deaths are those that are with people who have some type of terminal illness in which their death is not a surprise and is expected with usual course of disease progression. Entry-reentry deaths are used to describe persons whose illness trajectory is slower but they have periods of hospitalization and periods of better health. Glaser and Strauss were the first to begin to identify and describe these trajectories of how people die. Additionally, they studied dying people and learned a great deal about how people who are dying feel about what is happening to them. (Refer to Chapter 3 for more information regarding this and other frameworks used to describe how people with serious illnesses perceive their health.)

### Types of Illness Trajectories

Although Glaser & Strauss were the first to identify trajectories of dying, much work has been done since their initial description. These trajectories can also be referred to as illness trajectories. June Lunney and colleagues (Lunney, Lynn, & Hogan, 2002) used data from Medicare decedents and proposed the following four trajectories (Figure 2.1) as the most common patterns of illness progression:

- Sudden death
- Terminal illness
- Organ failure
- Frailty

#### Sudden death

This trajectory is characterized by no prior warning or knowledge that death is imminent. People are at a high or normal level of functioning right until death occurs. This is most common with accidents and other unexpected deaths.

#### Terminal illness

This trajectory is most common among patients living with an illness that can be categorized as leading to terminal, such as cancer. Functioning remains fairly high throughout the course of illness and then patients rapidly decline weeks or sometimes even days before death. Hospice care was developed based on this type of trajectory, which will be discussed in the next section.

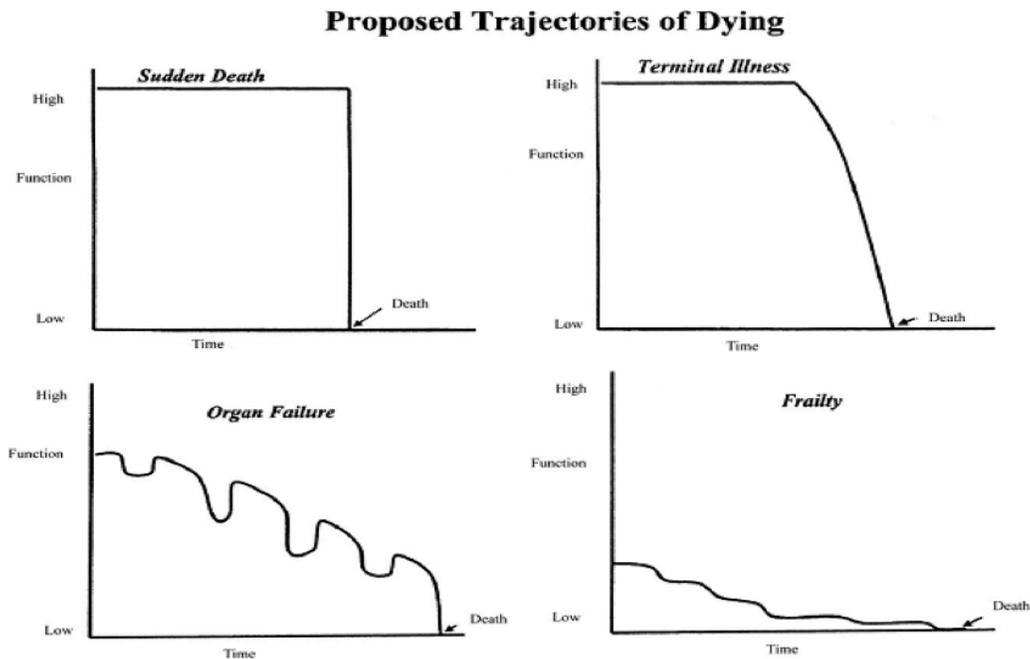


Figure 2.1 Proposed Trajectories of Dying. Reprinted with permission from Lunney, Lynn & Hogan, 2002.

### Organ failure

This trajectory is very common among many people in this country who live with a chronic illness which will eventually progress to death. Heart failure and chronic obstructive pulmonary disease are the most common illnesses that follow this type of progression. These illnesses can also be known as exacerbating-remitting, which simply means that they experience periodic exacerbations (flare-ups or worsening) of their illness which often leads to hospitalization. The symptoms eventually improve but over time, there is a gradual decline in the overall health of these individuals. Patients with this type of trajectory, particularly those with heart failure, have an increased risk for sudden cardiac death (Tomaselli & Zipes, 2004).

### Frailty

This trajectory is characterized by a slow decline towards death with low functional ability through the majority of their illness. These patients often live with progressive disability and require maximum assistance and care for a long period of time before their death. Patients with a general frailty and decline of all systems, such as with older adults afflicted with multiple conditions, can be categorized with this pattern. Patients diagnosed with dementia or Alzheimer's disease also have a prolonged period of decline and low level of functioning. Patients with this type of trajectory often die from complications associated with being totally dependent in all activities of daily living. They have also been found to

have higher rates of pressure ulcers and pneumonia from being bedbound and with prolonged use of feeding tubes (Rhodes, 2014).

As mentioned before, it is important for nurses to have an understanding of which trajectory describes their patient's illness. Each of these trajectories will vary in their overall course and presentation and a basic understanding about how they differ will be helpful for the nurse to be able to plan individualized care for their patient. In addition, it is important to understand the common experiences of people living with these various trajectories and the experiences of the family members who care for them. Nurses who care for patients at the end of life should have a basic understanding of the concerns common to people with certain types of illnesses. This will help the nurse better prepare for the care needs of these patients and their families.

### Illness Trajectories and Hospice

Hospice enrollment is structured by policy, both related to governing reimbursement agencies such as Medicare and Medicaid, and also within the individual hospice agency (Scala-Foley, Caruso, Archer, & Reinhard, 2004; Lorenz, Asch, Rosenfeld, Liu, & Ettner, 2004). Historically, the Medicare hospice benefit was structured to fit a specific type of problem—the illness trajectory of those afflicted with cancer (National Health Policy Forum, 2008). This is described as the terminal illness trajectory in Figure 2.1. As the decades have progressed, the scope of end-of-life care has expanded and includes patients with other types of trajectories that are different, such as patients with chronic illnesses, such as heart failure.

Since hospice care in this country was developed based on the terminal illness trajectory, many of the rules and regulations that govern the Medicare hospice benefit do not meet the needs of patients who are afflicted with an illness depicted by one of the other trajectories. For instance, the goal of hospice is to improve a person's quality of life through adequate management of symptoms. In patients with a terminal illness trajectory, many of the medications used to manage adverse symptoms are those to treat pain and anxiety. In patients with an organ failure trajectory, many of the medications that are used to manage symptoms are not pain medications, but medications to reduce the workload of their heart and/or reduce the fluid build-up around their heart. The current hospice benefit reimburses specific medications for use in hospice, with pain and anxiety medications being the most common. Other medications that are used for symptom management in illnesses, such as heart failure, are often not reimbursed with hospice because they are considered curative medications, rather than medications used for symptom management. So in trajectories such as this one, the medications that are used to manage the symptoms associated with the illness are not covered or allowed with the hospice benefits. This dissuades many individuals afflicted with non-cancer illness trajectories from electing hospice care. To date, there have been no substantial changes made to this policy to allow it to fit those other illness trajectories very well.

Currently, prognosis and patient preference are part of the main inclusion criteria that have to be in place in order for people to access the Medicare Hospice Benefit. The Centers for Medicare & Medicaid Services have designated four conditions that need to be met for an individual to be covered under the Medicare Hospice Benefit: (a) the individual must be eligible for Medicare Part A, (b) the individual must be certified as having a terminal illness with a 6-month or less prognosis if the illness runs its usual course, (c) hospice care must be received from a Medicare-certified hospice provider, and (d) the individual must waive their right to all Medicare payments for curative care, electing only comfort care through hospice (Centers for Medicare & Medicaid Services, 2013).

### **An Understanding of Illness Trajectories in Nursing Care**

So now that you have a basic understanding about illness trajectories, how can that knowledge be used when planning and implementing care for your patients? Although the nurse will not typically be the clinician who provides prognostic information to the patient answering the question “How long do I have?”, you should be prepared to address the question “What will happen?” Educating the patient and family does not stop during end-of-life care. There will be many areas that patients and families will need to learn about in order to promote the best quality of life. In addition to teaching patients about various medications used for symptom management, strategies to address nutrition and hydration needs, and a host of other topics, the nurse should be able to tell patients what they might expect over the next few months, weeks or days, if applicable. This can include both physiological and psychological signs and symptoms, in addition to practical aspects of how their activities of daily living will change and what kinds of care they should anticipate they might require.

Some patients and families may want to know every detail about what to expect, including how their death might actually happen. Others might prefer to know this information in smaller doses, as they begin to exhibit signs and symptoms that would require patient care teaching. It is very important to ascertain the patient’s desire for this information including level of detail. It is not wise to delve in to very detailed accounts of the dying process very early on, as this may frighten the patient and cause undue anxiety. If, however, patients want to know, the nurse should provide that information in a sensitive manner. There is a plethora of educational brochures and information available on this topic. Nurses should check with their institutions to obtain educational materials to have on hand to give to patients as the time arises. Now we will go through some commonalities that patients and families may experience with each of the four illness trajectories.

#### **Sudden death**

With this illness trajectory, you might or might not have provided any care to the patient who has suddenly died. You may be the nurse in the Emergency Department who was assigned to the patient who had already died in route to the hospital or whose death had been called following an unsuccessful code. If the patient is alive at the time of the interaction, the nurse must be sure to provide as much support and comfort as they can in the

midst of the likely chaos that will be happening. The nurse must never forget that their patient is an actual individual with a life and a family, as they are busily working with the health care team to save his or her life. As things may progress, the nurse should take time to let the patient know what is being done and that they are not alone. Instead of just standing in the corner as other clinicians perform cardio-pulmonary resuscitation on the patient, the nurse should proceed to the head of the bed and provide reassurance that they are present with the patient. Often the patient may be unconscious at that point, but we cannot say with certainty what they can or cannot hear, so be mindful of what is said during that period of time. Following the death, be sure to provide respect and dignity during post-mortem care. Communicating with the family of a deceased patient can be one of the most challenging and difficult encounters a nurse will experience, as with a sudden type of illness trajectory the death was not expected. This means that the family was likely not present or with the patient before or at the time of death, depending on the policy that governs family presence at the bedside within your institution. There can be a lot of emotional and psychological stressors associated with the family members of patients with this type of death. Family members might not have been able to say their goodbyes or to mend any differences before their loved one died. There might be guilt associated with this; and if family members were also involved in an accident and survived, they may experience survivor's guilt. Survivor's guilt is a common reaction to a sudden and/or traumatic loss in which the person left behind feels guilt that they survived and their loved one did not (International Society for Traumatic Stress Studies, 2005). Families experiencing difficulty coping after the sudden death of their loved one often have alterations in the normal grieving process and may likely need to seek assistance in helping deal with the loss.

### Terminal illness

Patients with this type of trajectory usually have some type of cancer. Their decline is typically short, often only a few weeks or days before they die. As you can see in Figure 2.1, the patient remains at a high level of function until that sudden sharp decline before death. One of the most important pieces of information that a nurse can give patients and families with this type of trajectory is that the end of life often comes quickly, without much warning. Most patients who are living with cancer receive treatment and diagnostic testing, followed sometimes by a break and then more treatment, and the cycle continues until the cancer goes into remission. If the cancer is at an advanced stage, there may be no break in treatment. Patients with end-stage cancer will usually continue their treatments until all curative options are exhausted, their lab values indicate that they are unable to receive further treatment due to low blood counts, or their cancer progresses despite all of the before mentioned interventions. It is often at the point at which the patient is informed that the cancer is spreading, or that there are no other treatment options, that the terminal decline towards death begins to happen. The important factor to explain to patients and families is that a person can be alright one day (or at least holding his own) and then bedbound the next day and actively dying. Thus the period of decline and disability is rapid and often chaotic if

patients and families are uninformed that this commonly happens with this type of trajectory. Families of patients with this trajectory often take on the role of caregiver quickly and are usually aware that death is nearing and have the time to make amends and say goodbye. Taking on the caregiver role during this time instead of just being the patient's spouse or son or daughter can cause emotional distress in family members. Depending on the setting, you can try to offer assistance with basic caregiving tasks, or perhaps institute a nursing assistant or tech to help the patient with those needs. This will help the family member to just be with the patient as the family member rather than as the caregiver.

### Organ failure

This type of trajectory may be the most common you will see in acute care settings. This trajectory is characterized by chronic and progressive illnesses that have periodic exacerbations that frequently result in inpatient hospitalization. Patients with this type of trajectory live with their illness for several years and go through many ups and downs during that time. Although patients recover from their exacerbation and get discharged from the hospital, there is a gradual decline in functional status over the years. So with each exacerbation, patients never really return to the same level of function they were previously. Over time, these exacerbations become more frequent and patients have more difficulty bouncing back. There is much difficulty with prognostication among these patients, as even experienced physicians cannot say with certainty if patients are at the end of life. Additionally, many of the medications that these patients receive for symptom management during an exacerbation are considered to be curative and are not covered by the current Medicare hospice benefit. This factor detours some patients with this type of trajectory from electing to have hospice care.

Educating patients and families is very important because these patients usually have a higher risk of sudden death (particularly with a cardiac diagnosis). These patients are also used to going to the hospital to get "fixed up" for exacerbations. Since this illness trajectory has a less predictable course than other trajectories, we never know if the next exacerbation could be the last. Assessing whether patients have an advance directive is very important because of the unpredictability of this type of trajectory. Since prognosis is not commonly talked about with these types of illnesses, patients might not be aware of their options and perhaps have not considered making an advance directive. Additionally, the risk of death following an exacerbation is great for this type of trajectory and often, as mentioned before, unexpected. Families may have a difficult time understanding why their loved one did not bounce back this time. It is important to educate patients and families about illness progression with this type of trajectory in a way that informs them but does not completely rob them of hope.

### Frailty

Patients who have this type of trajectory often live with their illnesses for many years. Ill-

nesses that comprise this progression often disable patients early on and patients live with a low level of functioning for many years, requiring maximum assistance. This assistance and care is usually provided by family members and/or patients become institutionalized in long term care facilities. Caregiver burnout is often a problem and family members require a lot of emotional support as well as practical support and assistance. Offering any type of community resource or respite care for these families can be a great deal of help. Patients themselves might be afflicted with cognitive impairments which can lead to many adverse events. Most require assistance in most activities of their daily living.

Patients with this type of trajectory may get to a point in which they are no longer able to swallow and require artificial means of nutrition and hydration. The use of feeding tubes is a sensitive subject and can cause many ethical dilemmas for healthcare personnel and families alike (Rhodes, 2014). Often helping families evaluate the quality of life of their loved ones is one way that nurses can help families with their decision making about whether a feeding tube is appropriate. Families often struggle with caring for their afflicted loved ones for many years and the nurse should always keep this in mind when planning and implementing care for these types of patients.

### What You Should Know

- By understanding illness trajectories, the nurse will be able to develop an individualized plan of care for the patient who is nearing the end of life.
- Sudden death, terminal illness, organ failure, and frailty are the four most common types of illness trajectories found in end-of-life care.
- The current Medicare hospice benefit was developed based on a terminal illness type trajectory and its regulations may not be as well suited for patients with other illness trajectories.

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### 3

## Conceptual Frameworks Guiding Death & Dying

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It's only when we truly know and understand that we have a limited time on earth—and that we have no way of knowing when our time is up—that we will begin to live each day to the fullest, as if it was the only one we had.

-Elisabeth Kubler-Ross

### Learning Objectives

- Define what a theory is and explain its relationship to patients with serious illnesses.
- Explain how nurses and clinicians can use theories for their care of patients.
- Describe the premise of quality of life and uncertainty in illness.
- Identify the five stages of grief.
- Describe what death awareness is and its relationship to end-of-life care.

People who are living with a serious or life-limiting illness have to deal with a lot in the course of their daily lives. Often, daily events such as preparing a meal or taking care of errands are burdens instead of normal parts of the day. The way that people understand and cope with their illness varies from person to person. Some people do well and some do not; it is a multi-factorial process. In nursing and healthcare in general, scholars have developed ways that can help clinicians to better understand how people react to their health and illness, which can help us understand why some people do better than others. These commonalities in the way that people behave can be explained by conceptual frameworks or theories. Sometimes called a model, a theory is an abstract generalization that aims to offer

an explanation about the relationship between phenomena (Polit & Beck, 2014). A theory is usually a depiction of interrelated concepts in a manner meant to predict or explain a relationship among them.

Theories can be useful tools for nurses and clinicians because they can provide useful information about the patients we care for. People who live with serious illnesses have some common factors that can affect their lives and the way they live with their illness. There have been several theories developed that have aimed to describe the ways people react to their illness and cope with the knowledge of their impending death. Nurses and clinicians should become familiar with these theories in order to better understand how their patients are dealing with these issues. Although each patient is an individual and may not behave entirely like what is described in a theory, it is useful for the nurse to be aware of how the majority of people deal with these issues. This will enable the nurse to better anticipate the needs and concerns of patients who are going through similar life events. In this chapter, we will begin by looking at a few theories that deal specifically with the quality of life and uncertainty in illness; often these two phenomena are very important for patients living with a serious illness. Then we will examine some specific theories that affect people whose illnesses progress to the terminal stage. These theories focus on various aspects of the death and dying process including stages of grief and death awareness.

### Quality of Life Model

Quality of life (QOL) is a multi-dimensional concept that includes the physical, psychological, social and spiritual functioning of a person (U.S. Department of Health and Human Services, 2014). People who live with a serious illness often have various stressors that can affect one or several of these dimensions. Understanding a person's quality of life can help nurses and clinicians plan appropriate care to meet the specific needs of that individual. Quality of life can differ from person to person, so perhaps an illness that affects one person's psychological dimension might not affect another person with the same type of illness in the same way. Only individual patients can determine which aspects of their quality of life are affected. As nurses, we often witness things that we might perceive to be stressors or problems that need to be solved. We should never assume or be the judge of another person's quality of life. What is important to one person, or to the nurse, may not be important to another. Even though the nurse may feel that their patient's social quality of life is negatively affected, they need to ask the patient and not just assume.

### Uncertainty in Illness

The concept of uncertainty in illness was developed by Merle Mishel in the early 1980's and has been the focus of many scientific studies (Mishel, 1981). The role of uncertainty in a person's experience with illness, hospitalization, and treatment was examined by Dr. Mishel and led to the development of this theory. The uncertainty that accompanies chronic illness has been identified as living with "continual uncertainty" (Mishel, 1990) and appraised as either "danger" or "opportunity." In people living with a chronic illness, for example, exac-

exacerbations are often perceived as a “danger.” Willems, Hak, Visser, & Van Der Wal (2004) found that the majority of patients with congestive heart failure have thoughts about death only during their exacerbations. After recovery, these patients returned to another period of stability during which time the immediate “danger” that was once perceived was gone. In another study, patients with advanced heart failure viewed their future as unpredictable and uncertain (Dougherty, 2007). Their concerns about the future were related to fears surrounding the communication of health information from their providers. Some participants expressed fear and uncertainty about inquiring about information related to their prognosis and future.

People with chronic illnesses often wonder about what the future with their illness will be like. In a study by Curtis, Engelberg, Nielsen, Au, & Patrick (2004), 115 patients with severe pulmonary disease reported their need to receive better information about what to expect with illness progression and about what dying might be like. They were aware of the progressive nature of their illness; however, they had great uncertainty about what to expect with their future functional status and how they might actually die. In contrast to the study in which heart failure patients only thought about death during exacerbations, patients with chronic pulmonary disease are often thinking about the next exacerbation and if it will be their last. In a study by Oliver (2001), patients reported fearing every exacerbation as the one that could end their lives. The concept of “fear” was reported in many studies that explored the perspectives of people living with chronic obstructive pulmonary disease (Seamark, Blake, & Seamark, 2004; Guthrie, Hill, & Muers, 2001; Habraken, Willems, De Kort, & Bindels, 2007). The uncertainty in prognosis and illness progression seems to go beyond just a life expectancy estimate for many people who live with serious chronic illnesses.

## Stages of Death

In 1969, Dr. Elisabeth Kuebler Ross wrote a book entitled *On Death and Dying* in which she outlined a conceptual framework for how individuals cope with the knowledge that they are dying (Kuebler-Ross, 1997). She proposed five stages of this process that included denial, anger, bargaining, depression, and acceptance. Not all people will go through each stage in sequence, and some may skip some stages altogether. It is important for nurses who care for patients who are dying to have an understanding about these stages in order to be able to properly care for and support themselves and their families.

### Denial

Denial is the first stage because many individuals will initially react to being told that they may die by denying what they heard. People in this first stage will be in disbelief and think that their doctor has made some kind of mistake. Often patients will go to another doctor for a second opinion during this stage. Denial can be important for two reasons: it will initially be somewhat of a shock absorber enabling the person to seek clarification about the truth in what they were told. It can also provide patients with the needed time to become

acquainted with the possibility that the information they heard is true which can enable them to internalize and begin to process that information.

### **Anger**

Anger is the second stage and can be the most difficult for clinicians and caregivers to witness. In this stage, individuals have accepted that the news of impending death is true and they are naturally angry about it. They do not understand why they have to die, and they make this known to those around them. They may lash out at clinicians and loved ones alike because they are angry about their situation. Often, nothing that clinicians or family members do for them is right and they have negative things to say about other aspects of their life as well. Patients in this stage realize that they have lots of things in their life that they wanted to accomplish, but now they will not have the time.

### **Bargaining**

The third stage is called bargaining, and it is a stage that is rarely visible to onlookers as it happens internally within the person who is dying. In this stage, individuals realize that they are past denying that they are dying and that they have been angry about it, with neither of the two causing any change in the outcome. Patients at this stage may bargain with a higher power to change their outcome and give them more time. Sometimes patients might bargain with their doctor to try to find any other option that might give them more time, but this bargaining is often accomplished internally between the dying patient and their higher power or God.

### **Depression**

Depression is the fourth stage and is a natural part of learning that impending death is near. Patients might be saddened because they had things they wanted to accomplish, places they wanted to go, or people they wanted to see, and those things will now be cut short. In addition, patients may be experiencing decline in physical abilities, loss of function, and increased symptoms such as pain. Those are factors that can lead to depression even in people who are not dying, and are even more magnified in those who are dying.

### **Acceptance**

The final stage is acceptance. This stage does not mean that the person is happy about their impending death, but rather that they have come to accept it and have found a sense of peace with it. The first four stages involved mostly negative emotions which have taken a toll on the patient. Time has progressed and patients can begin to move past the negative emotions and focus on the time they have left. During this stage, their hope for a cure is replaced by a hope that their final days will be peaceful and their death will be what they want it to be.

There are some important actions that nurses and clinicians can do during each of these stages to support the patient and their family. Table 3.1 outlines each stage and the associated actions that nurses can do to help.

Table 3.1 Nursing Interventions for the Stages of Dying

<i>Stage of Dying</i>	<i>Nursing Interventions</i>
Denial	Actively listen to patients' concerns and provide support as needed
	Be sensitive to patients' thoughts and ideas even if medically unrealistic
	Patients need to feel like they are being understood and accepted
Anger	Educate and support the family who may be on the receiving end of the patient's anger
	Tell them that this is a normal part of the process and that the patient is angry at impending death and taking it out on those closest to them
	Respond to the patient's anger in an accepting but non-provoking manner and realize that the anger is not at the nurse but at the situation
	Approach the patient in a pleasant way without being overly cheerful; rather use the patient's expressions to gauge your own expressions during interactions
Bargaining	Since this stage often occurs internally, there may not be any particular action indicated on the part of the nurse
	If the patient brings up the topic of God or spirituality, provide active listening and emotional support
	Pray with the patient if comfortable with doing so and if requested.
Depression	Avoid clichés; do not urge patients to "cheer up" or "look on the bright side"
	Realize that nothing you do is going to take away their impending death and that your actions may be more meaningful to patients than your words
	Educate the family about this stage and let them know that trying to cheer their loved one may not be helpful. Instead encourage the family to be supportive without trying to cheer the patient up
Acceptance	Patients may benefit from more non-verbal forms of communication such as quietly sitting with the patient, holding their hand, lightly stroking their back
	Continue to anticipate the patients' needs and address any concerns

	Continue to provide emotional support to the patient and family
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### Death Awareness

In 1965, researchers Glaser & Strauss examined the context surrounding patients' awareness of dying in the hospital setting. Using grounded theory methodology, they conducted interviews and participant observation on the interactions between patients and hospital staff. Their findings led them to describe the following four contexts of awareness of dying: closed awareness, suspicion awareness, mutual pretense awareness, and open awareness.

#### Closed awareness

Closed awareness occurs when clinicians fail to disclose prognostic information to the patient. The patient is kept in the dark about their poor prognosis and impending death. Health care clinicians are careful not to say anything to the patient that would make him or her aware that their death was near. Patients often begin to suspect that they are not being told everything, particularly if the nurses and doctors appear secretive in their conversations. This may lead to the patient to move to the next context of awareness.

#### Suspicion awareness

The patient has suspicions about his overall prognosis and health status in this context and begins to realize that he is not being told this important information. This might lead the patient trying to find out the truth by asking various staff members direct or indirect questions that could provide information about their suspicions. Often patients will try to trick the staff member into telling them something. For example the patient may tell the nurse that the doctor said that their illness is very serious, in efforts to either prove or disprove their suspicions.

#### Mutual pretense awareness

In this context, both the patient and the clinician are aware that the other party knows of the poor prognosis or impending death. Instead of acknowledging it openly, both parties pretend that it is not true and continue to act as though everything was normal. This arrangement acts as a coping mechanism for the patient, who might not be ready to openly discuss the poor prognosis.

#### Open awareness

In open awareness, both the patient and health care clinician are aware of the poor prognosis or impending death and openly acknowledge it. This context allows both parties to openly talk about the prognosis, which could be beneficial to the patient in coping and acceptance of his situation. This context is also better for the staff member as they do not have to be careful not to get caught speaking about prognosis as in closed awareness, nor do they have to lie to the patient if they ask outright about their condition.

### Recent Research on Death Awareness

There is a growing body of literature on prognosis and death awareness for both the patient and their family. In 280 patients with advanced cancer, there were no significant differences in reports of peacefulness between patients who were and those who were not aware that they were terminally ill, however the families of patients who were aware reported higher quality deaths than those who were not (Ray, Block, Friedlander, Zhang, Maciejewski, & Prigerson, 2006). In this sample, only 49 out of the 280 patients reported being aware of their terminal condition, which means the majority of patients were unaware.

People with exacerbating remitting trajectories have been found to be even less aware of possible death than those with cancer. In a study that compared the needs of patients with lung cancer and COPD, three-fourths of those with lung cancer knew that they might die and had been given more accurate prognostic information (Edmonds, Karlsen, Khan, & Addington-Hall, 2001). Only 8% of patients with COPD were told they might die by their physician versus 30% of patients with cancer. In another study that retrospectively explored the perspectives of family members of those who died with COPD, over half the participants reported not being aware their loved one might die, 78% of whom would have wanted to know that information (Elkington, White, Addington-Hall, Higgs, & Edmonds, 2005).

A commonality that was found in studies that examined death awareness in patients was their open acknowledgement of future death. Interestingly, participants reported their deaths would result from their increasing age, not from their serious illness (Agard, et al., 2004; Gott et al., 2008; Murray, Boyd, Kendall, Worth, Benton, & Clausen, 2002; Rogers et al., 2000). It is uncertain whether this suggests that people do not understand the likelihood of death from chronic life limiting illnesses, such as heart failure for instance, because of poor communication about the illness or because they do not believe what they have been told.

### Readiness to Die

The need to better understand the experience of patients confronted with impending death was examined by Copp (1997). She sought to explore this experience particularly from the nursing perspective and exploring the nurse-patient relationship within the context of patients living with impending death. Copp found that patients who knew they were going to die at an uncertain time made many references to a separation between their *body* and their *self*, as though they were separate entities. This split in between oneself and one's body was examined closely to better understand the individuals' readiness to die. The readiness to die theory was based on four patterns or modes that individuals could be going through at any given time that relate to the degree of readiness of their body and their self to death. Dying persons could only be in one mode at a time but could change between modes as

their illness progressed and as they came to terms with their mortality. These four modes are organized by:

- Person ready, body not ready
- Person ready, body ready
- Person not ready, body ready
- Person not ready, body not ready

It is quite possible that death could occur within each of the four defined modes; however, as clinicians we could only hope that the majority of our patients would be within the “person ready, body ready” mode. In this mode, both the patient’s body and the patient’s internal self are aligned as being ready. Copp’s theory provides a different way to think about how patients who know they are going to die might be processing that information.

### What You Should Know

- Theories, such as the Quality of Life Model and Uncertainty in Illness theory can help nurses understand commonalities in the illness experience of their patients.
- Patients can go through 5 stages of dying including: denial, anger, bargaining, depression and acceptance.
- An open awareness of dying often has the best outcomes for both the patient and clinician.

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## Models of Organized End-of-Life Care: Palliative Care vs. Hospice

“

You matter because you are you, and you matter to the end of your life.

-Dame Cicely Saunders, Founder of the Hospice Movement

### Learning Objectives

- Define palliative care and hospice care.
- Compare the similarities and differences between hospice and palliative care.
- Identify the advantages and disadvantages between hospice and palliative care.

As mentioned in the first chapter of this book, end-of-life care is a broad term used to describe specialized care provided to a person who is nearing or at the end of life. The following terms have been used in both clinical and research domains that fall within end-of-life care: palliative care, supportive care, comfort care and hospice care. For the purposes of this chapter, we will focus on the two most widely recognized and used among these terms: palliative care and hospice care. These two models of end-of-life care are not the same, though they are commonly misconstrued as such among the lay population as well as within the health care community. While both types of care operate under the same philosophical idea, each functions differently within the health care system. One of the main goals of this chapter is to help the reader understand the similarities and differences between hospice and palliative care. Nurses who care for patients nearing the end of life are in an

ideal position to educate patients, families and other clinicians about these two formal end-of-life care programs.

### Palliative Care

The term palliate is defined as “to reduce the violence of (a disease); to ease (symptoms) without curing the underlying disease” (Merriam-Webster, 2014). Palliative care is a broad philosophy of care defined by the World Health Organization as an approach that improves the quality of life of patients with life-limiting illnesses and their families through the prevention and relief of physical, psychosocial and spiritual suffering (World Health Organization, 2014). Palliative care, by definition, is the underlying philosophy for providing all aspects of comfort to a person living with a serious illness. Although palliative care is the underlying philosophy of most organized EOL programs such as hospice, it has become a healthcare specialty and care delivery system over the past decade. In the U.S. today, over half (55%) of all 100-plus bed hospitals have a palliative care program, and in hospital palliative care programs have increased by 138% since 2000 (Center to Advance Palliative Care, 2011).

Palliative care uses a team-based approach to evaluate and manage the various effects of any illness that causes distress. Patients who live with serious illnesses often have pain and other symptoms which require attention in order to improve the person’s quality of life and reduce any undue suffering. Patients with serious illnesses may also need emotional support to help them deal with the various decisions related to management of their disease. Palliative care clinicians can assist patients and families with these important care needs. Palliative care can be used with patients of any age and with any stage of illness with the overarching goal of improving the patient’s quality of life (Center to Advance Palliative Care, 2011). Thus there is no predetermined life expectancy required to be eligible for palliative care.

As mentioned previously, palliative care programs have increased steadily over the past decade in U.S. hospitals. Usually comprised of physicians, mid-level providers, and nurses, palliative care consultation teams obtain referrals to evaluate hospitalized patients who have some type of need, such as symptom management, or assistance with decision making in light of a serious diagnosis. Additionally, some larger hospitals can offer palliative care consultation services to outpatients for similar services as well. In addition to hospital-based palliative care programs, palliative care services can also be found in most home health care agencies. Sometimes palliative care is associated with the home care agency’s hospice program, often employing nurses who are specialized in both. In home health care, patients with serious illnesses often get admitted to the palliative care team and as their illness progresses, may eventually transition to home hospice care. If part of the same program, patients will be able to have continuity in care and consistency with the same nurse, who can care for them from admission through discharge.

Several sub-specialties of palliative care have been developed over the past few years,

including pediatric and geriatric palliative care, which provide the same focus on improving quality of life in specialized populations, such as with children and the elderly. Palliative care is considered to be a specialty medical care but the way it is reimbursed differs from hospice reimbursement, which we will discuss more in the next section. Palliative care services are often paid for through fee-for-service, philanthropy, or by direct hospital support (ELNEC, 2010).

## Hospice Care

The term “hospice” originated from medieval times when it was considered to be a place where fatigued travelers could rest (National Hospice and Palliative Care Organization, 2014). Hospice is both a type of organized health care delivery system and a philosophical movement (Jennings, Ryndes, D’Onofrio, Baily, 2003; Herbst, 2004). Currently, hospice is one type of end-of-life care program supported by Medicare reimbursement that is geared toward providing comfort for those who are at or near the end of life. Hospice incorporates a palliative philosophy of care and is used by people with serious illnesses who are nearing the end of life.

According to the National Hospice and Palliative Care Organization (NHPCO), the focus of hospice is on caring for instead of curing a person’s terminal illness. With origins from the United Kingdom, the first U.S. hospice opened in 1971, and hospice programs have grown rapidly. By 2012, there were 5,500 hospice programs in the U.S. (NHPCO, 2013). In 2012, 57% of patients received hospice in a free-standing hospice, 20% in a hospital, 17% from a home health agency, and 5% from a nursing home (NHPCO, 2013).

Although a cancer diagnosis was the most predominant diagnosis among hospice patients since hospice originated, the rate of hospice use among non-cancer diagnoses has significantly increased. In 2012, cancer diagnoses accounted for 36.9% of hospice admissions, whereas the remaining 63.1% were attributed to non-cancer diagnoses. Debility, dementia and heart disease were the top three of the non-cancer diagnoses among patients admitted to hospice care (NHPCO, 2013). Unlike palliative care, hospice is usually reserved for people who have a prognosis of 6 months or less, and a formal certification by a physician is required to be eligible for hospice care. The average length of stay for a patient from admission to discharge on hospice care is approximately 18 days, or roughly 3 weeks (NHPCO, 2013). Patients who are eligible for and who elect to receive hospice care can receive many services that are focused on promoting comfort and improving their quality of life. As with palliative care, hospice also uses a team approach and usually consists of a physician, nurse, and social worker as the main clinicians that are involved in their care. Additionally, they are eligible to receive other services as needed and requested by the admitting nurse. The following is a list of the usual covered services available to patients who elect the Medicare hospice benefit:

- Physician services (patients can elect one primary physician as their hospice provider)
- Nursing care
- Medical equipment and supplies related to the terminal illness
- Medications for management of pain, symptoms, and comfort
- Hospice aide services
- Physical and occupational therapy
- Social work services
- Dietary counseling
- Spiritual counseling
- Bereavement care

-Centers for Medicare & Medicaid Services, 2013

In addition to this certification, patients who elect hospice care usually have to be in agreement with forgoing all further curative life-sustaining medical treatments and only electing to receive palliative care interventions that improve their quality of life. The following are some of the curative type treatments that are NOT allowed once a patient is enrolled in hospice care:

- Inpatient hospitalizations for life-sustaining treatments
- Diagnostic interventions (x-rays, labwork, CT scans)
- Emergency room visits
- Specialist provider visits
- Outpatient services
- Ambulance services

-Centers for Medicare & Medicaid Services, 2013

When patients elect hospice care, payments for all of their care come from the designated money allocated to hospice from their medical insurance provider. The majority of patients who elect hospice are on Medicare, and Medicare has a special hospice benefit that covers hospice care for beneficiaries from a Medicare-certified hospice program. In 2012, 83.7% of all hospice claims were covered by Medicare, 7.6% by managed care or private insurance, and 5.5% by Medicaid (NHPCO, 2013).

### **Similarities and Differences between Hospice and Palliative Care**

Both hospice and palliative care provide specialized care and support for individuals living with serious illnesses using an interdisciplinary team approach. The main goal with both is to improve the quality of life for patients through interventions that focus on improving comfort and reducing the complications associated with their illness. Both programs are family-oriented, meaning that the care that is provided is intended to support both the patient who is living with the disease and the family who is caring for them.

Although palliative care is ideally implemented alongside curative care when a person is diagnosed with a serious illness, hospice care is reserved for persons who have a life expectancy of less than 6 months as certified by their physician and for whom curative medical treatments are no longer an option or are desired by the patient. Figure 4.1 depicts two models of care: the first is the model that most commonly occurs in which there is a shift in the focus of care from curative to palliative very close to death. The second figure depicts the more ideal model in which palliative care is initiated right at the time of initial diagnosis. Historically, the first model is what is usually followed, whereas there is a distinct time when the focus switches from aggressive medical care to comfort care provided by hospice.

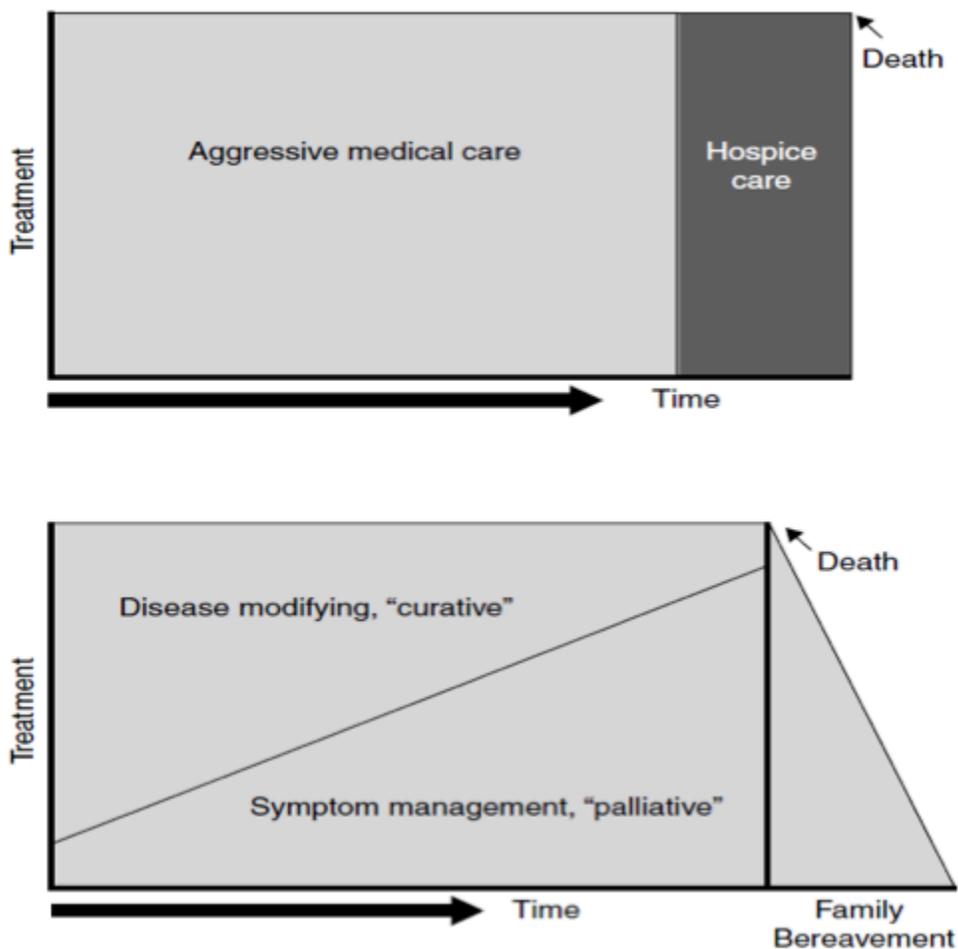


Figure 4.1 Models of Care (re-printed with permission from Lynn & Adamson, 2003 from RAND Corporation, Santa Monica CA).

Hospice care requires a prognosis of 6 months or less, whereas palliative care does not

have a prognosis requirement. Hospice requires patients to forgo all medical treatments that are considered to be life-sustaining or curative and the focus of care completely shifts to comfort-oriented care. With palliative care, patients can receive life-sustaining or curative treatments right alongside palliative care. Looking at the first image in Figure 4.1, you will see that there is a distinct vertical line separating aggressive medical treatments and hospice care along the illness trajectory. This shows that there is a distinct separation between curative and comfort care, which was how hospice originally was created. Historically, hospice care was developed for and used by people whose illness trajectory depicted a rapid decline towards the end of life, such as in cancer. In cancer patients, there is usually a time when the physician can determine that the cancer is worsening and the curative treatments are no longer effective. This is often the time that the burdens of the treatment outweigh the benefits. For example, despite aggressive chemotherapy, the patient's cancer continues to spread and is causing many adverse side effects. Often, patient's lab values fall into an unacceptable range in which chemotherapy is contraindicated. With these examples, it becomes clear to the physician that the patient is worsening despite treatment, and that it is likely the right time to switch to comfort care. It is at this time that conversations about prognosis and goals for care are initiated and the patient and family begin to make some difficult decisions.

The variability in the differing illness trajectories of people with non-cancer illnesses often makes the transition to elect hospice care difficult. Although there are more patients with non-cancer illnesses who are electing hospice than ever before, many patients continue to enroll in hospice late, or not at all. There has been an abundance of research on this area as to why these patients are not getting hospice care and the reasons include patient, provider and systems-related barriers to enrollment in hospice care. Referring back to the first image in Figure 4.1, that distinct line which separates aggressive medical care from comfort/hospice care is more difficult to evaluate among patients with a non-cancer illness. There is often not a time when the physician can say with confidence that the patient has a prognosis of 6 months or less of life. This can be due to the fact that most curative-type treatments may not lose their effectiveness or become a burden that outweighs the benefit in patients with non-cancer illnesses. In fact for certain types of diagnoses, such as heart failure, the curative type treatments actually provide symptom management. Patients with heart failure commonly have exacerbations in which they require hospitalization and administration of medications that are considered by hospice as being curative and therefore would have to forgo if electing to make the switch to hospice care. So while hospice is a wonderful care program for patients who are close to the end of life, it might not be able to provide the types of services that certain diagnoses, such as heart failure, have been using for symptom management to improve the quality of life.

If you refer to the second image in Figure 4.1, you will find the ideal way palliative care was meant to be used throughout the illness trajectory. Right from the time of diagnosis,

palliative care is also instituted. Although the level of palliative care may be small from the outset, it can increase throughout the trajectory of the individual as the aggressive curative treatments are decreasing. So as a patient's health worsens and their illness becomes more advanced, the level of palliative care will increase. As death approaches, curative care will decrease and palliative care will increase. The difference with the second image is that no distinct switch to palliative care is required because palliative care has been part of the overall plan of care from the time of initial diagnosis. This has been shown to be the most effective way to manage symptoms and care needs, rather than having a distinct separation in between cure and comfort.

The problem in end-of-life care is that all too often, the first image is what happens, and many patients with those non-cancer diagnoses are not receiving effective management for the symptoms and problems that go along with their illness. In order to improve the end of life experience for patients, it would be better to manage those symptoms and problems from the outset so that patients can be as comfortable as possible, educated about what they might expect, and have been given the opportunity to talk with a clinician about their goals for care before their illness becomes too advanced.

### **Advantages and Disadvantages of Hospice and Palliative Care**

As mentioned before, there is no universal reimbursement mechanism for palliative care, as there is with hospice. This may impede the ability for a patient to get palliative care from the time of initial diagnosis. Second, not all health care systems have a palliative care team or service, particularly the smaller and more rural hospitals. If palliative care is not available or not covered, patients will not be able to access it. This is partly why the first image in Figure 4.1 is what tends to happen in the illness trajectory. If electing hospice care means stopping all curative treatments, then patients and families will not opt for that until they are told that there is nothing else medically that can be done for them. Palliative care may be the best option for the patient at this time. Palliative care may be the better option initially for patients who have a serious illness which is still responding to medical treatments.

An advantage of electing hospice care is that patients who have minimal chance of prolonging their length of life due to their poor prognosis still have an option for care that will focus on their quality of life. Often people who have a life-threatening illness are told by their providers that there is nothing else medically that can be done to cure their illness. These words often make the patient feel as though they are stuck with dealing with their illness alone. They wonder what will happen to them if nothing more medically can be done. This can be a frightening thought, and one of advantages of hospice is that patients do not have to feel alone. Hospice can provide that support 24 hours a day, 7 days a week, and often just knowing that the nurse is just a phone call away can give significant peace of mind to patients and their families. Another advantage of hospice care are the various services that hospice can provide to patients. In home health care, hospice patients can have the most hours of home health aide services, which may be essential at the end of life in

order to help alleviate some of the burden of care from the family. The hospice benefit also pays for all medications and medical equipment needed to maintain and maximize patient comfort. This includes home oxygen which for patients who are not on a hospice program and have to meet a specific criteria for oxygenation status in order to be eligible. On hospice, patients have an entire team of clinicians who work together to plan and provide an individualized plan of care. Using an interdisciplinary approach enables patients to receive a holistic, high quality plan of care. Determining which one of these two formal end of life programs patients should use requires understanding the patient's individual goals and preferences for care. Once the clinician is aware of what the patient hopes in terms of their illness, then they can best advocate for their patient.

Although hospice and palliative care are the most frequently used services among patients who are at the end of life, it is possible to not use either one. Students often ask whether it is possible for patients to have what is considered a “good death” without being involved in a formal program such as hospice. Hospice and palliative care can assist patients and families to meet the various needs they will encounter during their final months of life, but are not mandatory. It is possible for patients to still have their goals and preferences for care met without hospice or palliative care involvement. However, patients would have to be well equipped with the knowledge of what they hope to accomplish and have healthcare professionals who are willing to listen to them and provide them that care. Patients who elect to not use either service should utilize a clinician with specialized knowledge in the areas that commonly require attention at the end of life, such as symptom management and psychosocial support.

### What You Should Know

- Hospice and palliative care are often misunderstood to be the same thing, but they are not.
- Both hospice and palliative care provide specialized care services aimed to improve overall quality of life for patients with serious illnesses.
- Although palliative care is ideally instituted alongside curative care when a person is diagnosed with a serious illness, hospice care is reserved for persons for whom curative medical treatments are no longer an option.

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## Initiating Conversations about Goals of Care

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Remind yourself that if you think you already understand how someone feels or what they are trying to say, it is a delusion. Remember a time when you were sure you were right and then discovered one little fact that changed everything. There is always more to learn.

-Douglas Stone

### Learning Objectives

- Define goals of care in the context of advanced illness.
- Identify various measures used by clinicians for prognostication.
- Describe how clinicians use the benefits and burdens of treatment to assist patients in determination of their goals of care.
- Identify strategies associated with the initiation of end of life conversations.
- Explain various factors associated with patients preferences for care.

Individuals come equipped with their own attitudes and beliefs about the things in life that are important to them. These include beliefs about who they are, what gives them meaning, what they value, and what they hold to be true. These priorities are what make people individuals, although many people likely hold similar things in high regard. These can include family and friends, good health, and general well-being and happiness. When a

person becomes seriously ill, the various stressors associated with their illness can take a toll on their overall priorities in life. Most people have an idea of what they want out of life and the things that they can accept and not accept regarding their personal well-being. When a person is diagnosed with a serious, life-threatening illness, they will have to consider what goals they hope to achieve related to their illness and what priorities they place on their current and future care. Many patients, however, do not realize the magnitude of their illness and/or the options they have for care. The role of the nurse or clinician is to educate patients and families about their illness and options for care based on their goals and preferences. Nurses need to ask patients what it is that they hope for and want within the context of their illness. It should never be assumed that nurses know what is best for their patient. Each person has their own set of values and ideals that may or may not change in the course of living with a serious illness. Many patients do not know what to ask and it is up to the clinician to help elicit these kinds of conversations with patients, always being sure to meet patients where they are in terms of dealing with their individual illness process. This chapter will focus on providing the student nurse or clinician with ways to initiate and facilitate effective conversations with patients regarding their goals and preferences for care.

### What are Goals of Care?

Goals of care are the outcomes that patients place the highest value on and would hope to achieve in regard to their illness. They are what the patient wishes for in terms of their illness. What is it that the patient would like to see happen with their illness, if there is no chance for reversal or total cure? What are the things they value as the most important in their lives? Would they rather focus on maintaining the quality of their life even if it means that the quantity of their life (or time they left) would be decreased? Do they want to continue to use all medical treatments necessary to increase their lifespan even if it will make them very sick? Having a patient ponder these questions will help them formulate and clarify their goals of care as they near the end of life. Often patients have not thought about what their goals of care are as they may have just been recently diagnosed with their illness or may have been too sick to consider what they might want. It is vitally important for the clinician to assist patients in formulating a plan for their care based on their values and preferences. Often this is done in conjunction with the family, who may or may not have their own goals for the patients' care; this can pose a challenge if there are significant differences between the two. In order for a patient to determine what their individual goals of care are, they have to know the severity of their illness, which includes their overall prognosis and life expectancy based on their terminal illness.

### Prognostication

ELNEC defines prognostication as the estimation of the future course and survival of an illness (ELNEC, 2010). Prognostication can provide the terminally ill patient with information regarding the usual course of their type of illness, including the most sought after question, *"How much time will I have left to live?"* Accurate prognostication of patients with

advanced illnesses has been a challenging element in the ability to provide quality options for care at the end of life (Willems, Hak, Visser & Van der Wal, 2004). Even the most highly skilled physicians cannot pinpoint the timing of a patient's expected passing, and a patient's reaction to a prognosis is similarly unknown. A patient may want to know the timeline of their disease's progression, and yet may not believe it. On the other hand countless patients believe firmly that no one on this earth can tell how long they have left and the only one who knows for certain is God. Yet many patients do want to be told how much time they have left; in fact, they expect to be told. Lowey and colleagues conducted a study examining the perspectives of patients with advanced illnesses and asked patients whether they wanted to be told if their illness got to the point where it was considered to be life threatening. Overwhelmingly, all participants in that study expected that their doctor would tell them when their illness became that severe. Most wanted to be told so they could re-evaluate their goals of care and plan for their future (Lowey, Norton, Quinn, & Quill, 2013).

As much as patients want to know prognostic information, it can be a challenge on the part of physicians to give accurate information. Christakis (1998) suggested many factors that are highly subjective and variable which relate to proper prognostication by physicians. The lack of consensus in defining "the end of life" was suggested to play a role in the difficulty with prognostication (Lamont, 2005). Prognostic uncertainty is the inability to determine and provide an accurate prognosis and it occurs with many illnesses that are chronic in nature, such as heart failure. This is due to the chronic exacerbating illness trajectory, in which a patient will have an exacerbation and then get better. This makes it more difficult for physicians to determine when the patient is nearing the end of life. One study found that even 3 days before the death of patients with heart failure, the median physician-predicted 6-month survival was 54% (Levenson, McCarthy, Lynn, Davis, & Phillips, 2000). More often than not, physicians tend to overestimate prognosis, particularly for patients with chronic end-stage diseases. In a sample of 468 patients with both cancer and non-malignant disease, only 20% of 343 physicians gave accurate (within 33% of survival) prognostic predictions (Christakis & Lamont, 2000). Since the risk of sudden death in people with heart failure is 6 to 9 times greater than in the general population (Lloyd-Jones, Adams, Carnethon, De Simone, Ferguson, & Flegal, et al., 2009), physicians have an even greater uncertainty regarding prognostication.

Despite being told prognostic information, many patients and family members have been found to overestimate or disbelieve what they are told. A large number of family caregivers did not believe or agree with the life expectancy estimation communicated to them by their physician in a study by Cherlin, Fried, Prigerson, Schulman-Green, Johnson-Hurzeler, & Bradley (2005). Even patients with an advanced illness seemed to underestimate the seriousness of their disease, with 36% of 103 cancer patients reporting their disease as being "stable or in remission" (Sapir, Catane, Kaufman, Isacson, Segal, Wein et al., 2000). Another study found patients with heart failure reported that understanding prognosis and life

expectancy information was not helpful in their coping or planning for care at the end of life (Dougherty, Pyper, Au, Levy & Sullivan, 2007). Just as prognostic information is unique to each individual, the manner with which people take in that information varies. On the other hand, family caregivers of terminally ill patients had different preferences regarding the need to be informed about the incurable nature of their loved ones' illnesses (Cherlin et al., 2005). In retrospect, some families wished they would have known the seriousness of the illness which ultimately lead to their loved one's death, while this was not important to others. Family members in another study also valued honest communication from the physician in a way that did not destroy all of their hope (Wenrich, Curtis, Shannon, Carline, Ambrozy, & Ramsey, 2001).

The majority of studies in this area focused on mortality as the endpoint of prognostic information. There was great variability in the literature among people with advanced illnesses about the need to know prognostic information. In a study by Gott and colleagues (2008), some of the patients with advanced cardiac disease were aware of their poor prognosis, but did not want to have conversations about explicit prognostic information regarding mortality. Another study found mixed views about the desire to know the prognosis among 20 patients with end stage heart failure (Horne & Payne, 2004). In a study by Rogers, Addington-Hall, Abery, McCoy, Bulpitt, & Coats et al. (2000), participants actually wanted and sought out prognostic information from the research interviewer regarding their illness. Although some patients do not want to know when they will die, many want to be informed about what it will be like for them as their illness progresses. The sense of uncertainty about what the future holds in general seemed to be a greater concern in patients living with advanced illnesses. It is unknown whether a sense of what the future holds as it relates to quality of life might have a greater effect on what options people choose as they near the end of life.

There are several predictors that physicians can use to help them be able to provide patients with an accurate prognosis. There are various instruments and tools available including the Karnofsky scale score (Karnofsky & Burchenal, 1949) which evaluates a patient's functional status on a scale of 0 to 100. A score of 100 indicates optimal performance status and a score of 0 indicates death. Patients with a score of 50 or below require considerable medical care. Patients' clinical signs and symptoms can also be used to estimate prognosis. Severe dyspnea at rest, dysphagia (inability to swallow), profoundly decreased appetite, decreased hydration status, and marked weight loss have been associated with decreased survival time among cancer patients (ELNEC, 2010). Abnormal laboratory values can also provide information to help assist the physician in estimating survival time. The literature also suggests that physicians ask themselves whether or not they would be surprised if their patient died within the next 6 months. If the answer is no, then that can also be used in conjunction with the clinical data to assist with prognostication.

## Benefits and Burdens of Treatment

Now that you have a basic understanding about what illness trajectories are and their relationship to hospice, we will discuss an important indicator of how clinicians can assist patients with deciding whether or not to continue disease driven treatments or opt for a more palliative form of care. The benefits of treatment are the positive aspects that the patient should receive in regard to that treatment option. These can include: total cure of illness, reducing the progression of illness, reducing the negative effects of another treatment on the illness, providing relief of symptoms associated with the illness, and increasing quantity of life and/or increasing quality of life. These benefits are mainly positive things that would result from undergoing the treatment option. The burdens of treatment can then be classified as the negative aspects of undergoing the treatment, which can include: progression of illness despite having the treatment, worsening of symptoms or development of additional/new symptoms while on the treatment, reduction in crucial and protective lab values such as red blood cells, white blood cells and platelets, and the burden physically, psychologically or emotionally that may result from engaging in the treatment.

Although there are usually some negative effects associated with most medical treatments, these should not outweigh the positive effects. This is how clinicians can weigh the benefits of treatment against the burdens. For example, a nurse has a patient with advanced cancer who undergoes a clinical trial that may or may not extend their life. The patient has undergone all other conventional treatment options and this clinical trial is the last option available to them. Although the short and long term effects are questionable with this treatment option, it may help to extend their life. If that is the goal of care for this patient, then this option may be ideal. Another example might be a patient who undergoes grueling chemotherapy which produces very negative side effects. The patient's next scan shows that the cancer has spread despite having the treatments and has reduced blood counts to a dangerous level. It is at this point that the burden of the treatment is outweighing any benefit that the treatment may have. The clinician can determine individual patient's benefits and burdens of treatment and can use that criteria as a way to assist patients with looking at prognosis and formulating their goals of care. Additionally, reviewing the benefits and burdens of treatment periodically may be required with illness progression as the patient may have to re-evaluate their original goals of care and make changes based on how their illness is progressing.

## Initiating the Conversation

Despite having a good understanding about a patient's particular illness trajectory and available treatment options, there will come a point in which a conversation needs to occur between the health care clinician, the patient, and the family. These conversations are inherently the most difficult kind that occurs between clinicians and patients, as most of the information exchanged in the conversation is based on negative news. Often the conversation is to inform the patient that their illness is progressing despite current treatment options

and/or all curative type of treatment options have been exhausted. Quill (2000) discussed the differences between urgent and routine indications for initiating an end of life conversation. Patients whose death was imminent, who talked about wanting to die, or who inquired about palliative care or hospice were identified as urgent indications for initiating a conversation about end-of-life care. In comparison, basic discussions about prognosis and treatment options were considered to be more routine indicators (Quill, 2000).

There is a large body of literature about communication between the patient and provider, particularly related to end of life discussions (Cherlin et al., 2005; Tulsky, 2005a; Tulsky, 2005b; Casarett & Quill, 2007). Often these conversations have been delayed until the patient's illness has become very advanced and the patient may be very close to the end of life. The difficulty in determination of prognosis and a delay in initiating the conversation can be challenging factors that have been found to contribute to hospice delays (Casarett & Quill, 2007). However, a growing body of literature suggests delays in hospice care for patients at the end of life is a result of poor communication about prognosis and options for care at the end of life between patients and physicians. Although 70% of cardiac patients described having a good relationship with their physicians, only 2 out of 80 patients reported having a discussion related to end of life (Formiga, Chivite, Ortega, Casas, Ramon, & Pujol, 2004). Casarett, Crowley, & Hirschman (2004) found that 75% of decedents received information about hospice care as an option at the end of life from a hospice care provider rather than their physician. The differences on the topics viewed as important between patients and physicians could have a role in these communication issues. Patients reported focusing more on outcomes of care rather than on treatments, whereas the physicians' focus was more on treatment preferences, particularly life sustaining interventions (Rosenfeld, Wenger, & Kagawa-Singer, 2000). Sapir et al. (2000) examined the expectations of patients with cancer regarding their oncology care providers and found 85% of patients to be satisfied about the information they received about their disease, with 90% reporting satisfaction with the manner in which that information was communicated. The majority of participants (98%) expected their oncologist to be skilled in diagnostic modalities, with 90-95% expecting providers to be considerate and tactful.

### Strategies for Effective Communication

The first step in effectively communicating with patients who are nearing the end of life is to determine how much information they want to be told. Many times patients will want to know the truth regarding prognosis but prefer not to hear the sensitive details. In order to effectively communicate with patients, the clinician should seek clarification about this before the conversation takes place. In exploring the preferences of patients with cancer and pulmonary disease about the communication of truthful information, Deschepper and colleagues found that patients prefer gradual information that is "dosed" to each individual person (Deschepper, Bernheim, Vander-Stichele, Van den Block, Michiels, & Van Der Kelen et al., 2008). Acknowledging and normalizing the uncertainty in the course of illness for

patients with exacerbating remitting illnesses such as heart failure can strengthen the communication process between providers and patients (Goodlin, Quill, & Arnold, 2008). The preservation of hope has been identified from both patients and providers within the context of communication of health information. Kutner, Steiner, Corbett, Jahnigen, & Barton (1999) found that although 100% of terminally ill participants wanted their physicians to communicate information in an honest manner, 91% of them also wanted their physicians to be optimistic. Physicians of patients with end stage COPD reported intentionally withholding bad news as a way to foster hope in the patients they felt needed it (Curtis, Engelberg, Nielsen, Au, & Patrick, 2004). Previous studies have found that patients with cancer generally wanted to know information about their illness, even if it was considered to be “bad news.” They also expected honesty and sensitivity from their provider during the communication process.

### Patient Preferences for End-of-life care

Patient decision making about treatment preferences, particularly related to life-sustaining treatments and resuscitation, has been examined with various sub-groups of people with advanced illnesses. The treatment preferences of middle-aged and older adults with advanced cancer were examined by Rose, O’Toole, Dawson, Lawrence, Gurley, Thomas, et al. (2004). The positive correlation between what patients wanted and preferred in regard to treatments compared with the care they actually received was only found to be strong with the older adult group. Treatment burden, type of outcome, and likelihood of outcome were found to influence decision making in end of life treatment preferences of patients with advanced illnesses (Fried & Bradley, 2003). Patients were more apt to accept burdensome treatment with the likelihood of good outcomes; however, they would be willing to accept more burdensome treatment with poorer outcomes as their illness worsened. This suggests that their health status influenced the values of the burden and benefits of the treatment; however, these values and perceptions seemed to change over time as they became more ill. So patients themselves can weigh the benefits and burdens of their treatment and use those to make health related decisions about their care.

Type of diagnosis was not found to be associated with treatment preferences in another study, but decreased functional status was positively associated with decreased preference for a high burden treatment (Fried, Van Ness, Byers, Towle, O’Leary, & Dubin, 2007). Bambauer & Gillick (2007) examined treatment preferences for care at the end of life with 86 patients receiving palliative care consultation and found the vast majority to prefer maximizing comfort (54%) and maintaining function (27%), with only 19% preferring to prolong life. The majority (56%) of this sample were patients with non-cancer illnesses, 23% of which were diagnosed with heart disease.

Patients with heart failure (83%) were found to receive more life-sustaining treatments, such as cardiopulmonary resuscitation, mechanical ventilation, vasopressors, and admission to critical care units, than patients with cancer (43%) (Tanvetyanon & Leighton, 2003).

Forty percent of elderly cardiac patients hospitalized during an exacerbation said they did not want to have CPR to sustain life, and 50% preferred to receive care at home if there was no hope for recovery from the exacerbation (Formiga et al., 2004). The majority of patients with advanced heart failure wanted life-prolonging treatments withdrawn or withheld when appropriate; however, the appropriate time was not defined (Willems et al, 2004). Seventy-six percent of heart failure patients with do-not-resuscitate (DNR) orders still received some type of life-sustaining treatment before death compared with those without any DNR orders. Cardiopulmonary resuscitation (CPR) was the only intervention that was significantly less frequent for patients with a DNR order. Interestingly, although the prevalence of DNR orders were similar between cancer and heart failure patients in this sample, patients with heart failure received DNR orders much later during their hospital admission than patients with cancer.

### What You Should Know

- Before any good plan for end-of-life care can be developed, nurses need to assess the patients' goals of care.
- Difficulties with prognostication can contribute to late referrals for palliative care or hospice.
- Previous research has supported patients' preferences to be told prognostic information, even if it is bad, in order to be able to make informed care decisions at the end of life.

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## **PART II**

# **In the Moment**



## 6

# Management of Pain and Physical Symptoms

“

The greatest evil is physical pain.

-Saint Augustine

### Learning Objectives

- Identify various types of pain and the pharmacological and non-pharmacological interventions used for management.
- Describe components of a comprehensive pain assessment.
- Explain barriers associated with effective pain management.
- Identify the most common non-pain symptoms associated with patients nearing the end of life.
- Describe the interventions used to relieve refractory dyspnea and terminal restlessness in patients nearing the end of life.

Perhaps one of the greatest concerns of patients who are nearing the end of life is pain and discomfort. Most terminal illnesses are associated with one or more physical manifestations of discomfort. For instance, patients with cancer usually have some type of pain, and patients with chronic pulmonary disease suffer from breathlessness. The International Association for the Study of Pain defines pain as “an unpleasant sensory or emotional experience associated with tissue damage” (IASP, 2014). Clinically, pain has been defined as what the patient subjectively says that it is. In a report by the National Center for Health Statistics, approximately 90% of patients being admitted to hospice care had their pain assessed at the initial visit; however, one-third of those patients continued to report pain near the time of their death (Caffrey, Sengupta, Moss, Harris-Kojetin, & Valverde, 2011). Pain is a symp-

tom that requires continual assessment and evaluation of the current interventions used for its management. As those who work with patients in pain know, the longer pain is left unmanaged, the more difficult it may be to treat. In addition to pain, patients nearing the end of life often have other types of negative symptoms including: dyspnea, cough, nausea and vomiting, constipation, anorexia and cachexia, dysphagia, fatigue, seizures, lymphedema, depression, anxiety and terminal restlessness or delirium. The aim of this chapter is to examine the current assessment and treatment options for pain and other symptoms that can occur in patients as they near the end of life. Additionally, we will discuss some common barriers associated with the pharmacological management of pain.

## Pain at the End of Life

### Types of Pain

Pain is usually classified in terms of its physiological mechanism (somatic, visceral, or neuropathic) and its temporal pattern (acute or chronic) (Coyle & Layman-Goldstein, 2001). It is important for the clinician to understand what type of pain is involved in order to be able to tailor their assessment and interventions for that patient. Somatic pain, also known as nociceptive pain, is often well-localized to one area, usually within deep musculoskeletal tissues. Bone pain is an example of somatic pain. Visceral pain is described as deep squeezing or pressure and is not as well localized to one area. It is often associated with the compression or stretching of thoracic or abdominal viscera. Pancreatic or liver cancer often causes this type of pain (Coyle & Layman-Goldstein, 2001). Lastly, neuropathic pain is associated with illness or injury to the peripheral or central nervous system, such as a tumor pressing on a specific nerve in a patient with cancer. Neuropathic pain is described as a sharp, shooting, or burning pain, often like an electrical shock that penetrates one's body. The management of pain is often dependent on the origin of the pain and which type of pain is involved.

Pain can also be classified in terms of temporal pattern. Patients can have both acute and chronic pain with more than one type or location of affliction. Acute pain is best defined by its onset. For the most part, the source of the pain can be identified and is often accompanied by other physiological signs and symptoms, such as trauma to the afflicted area. Acute pain often comes on suddenly from a well-identified cause. It is typically also short-lived, meaning that once the underlying problem is resolved and/or analgesia is initiated, the pain usually resolves. Sub-acute pain is a type of acute pain characterized by a slower onset, often over a few days, in which pain slowly escalates from mild to more severe. Another type of acute pain is called intermittent or episodic pain. Intermittent or episodic pain occurs only once in a while, often during a regular time period, such as cramping pain associated with the monthly menstrual cycle; or it may also occur irregularly, such as with a migraine headache.

Chronic pain often worsens over time, lasts for an extended period of time and is accompanied by having a negative effect on the patients overall functioning or quality of life (Fink

& Gates, 2010). Chronic pain can further be categorized as chronic malignant or chronic non-malignant pain. Chronic malignant pain is related to pain derived from a primary cancer or metastasis from cancer. It can also be a result from cancer related treatment, such as radiation. Chronic non-malignant pain refers to all other non-cancer chronic pain, such as chronic back pain, fibromyalgia or arthritis.

### Assessment of Pain

A thorough and comprehensive assessment of pain is by far one of the most important skills that nurses who care for patients nearing the end of life should possess. As mentioned before, pain is one of the most feared symptoms but also one that can be managed well following a thorough assessment and pain management plan. While there are a plethora of formal pain assessment tools that are used in practice, we will describe the necessary components of any good pain assessment plan.

#### Terminology

First, as clinicians it is important to remember that patients may not always use the term “pain” to identify their pain or discomfort. Sometimes this is due to cultural reasons and other times, it can be the patient’s way of denying the real pain they are feeling. It may be helpful for the clinician to re-word the question using another term for pain, such as discomfort or aching. For example, a nurse asks their patient a general question such as, “Mr. Smith, are you having any pain today?” He replies “no;” but when based on the objective signs the nurse is observing, they assess that he is having some type of discomfort. The nurse could then re-phrase the question as, “Mr. Smith, I understand you are not having any pain, but I notice you are holding onto your left arm and wincing when you move. Are you having any discomfort or soreness in that area?” A more direct question that incorporates your observations, as well as using a different term for pain, may be more effective in getting you an accurate answer.

#### Current and usual pain experience

Next, the nurse needs to gather all the necessary information about the pain. They will need to understand both the patient’s current pain level and their usual pain experience. This may differ and is especially important for those living with some type of chronic pain. What is their pain like today, and how is that pain in relation to what they usually experience? If the nurse is regularly assigned to this particular patient, they will become familiar with their usual pain experience; however, if the nurse is new to the patient, they will have to elicit that information. In end-of-life care, knowing the patient’s usual pain levels will help guide the interventions and next steps related to the patient’s individual pain management plan.

#### Location

Next, the nurse needs to assess the site where the patient is experiencing pain. This could be multiple locations, depending on the patient. The nurse will need to evaluate each site as a separate location, if applicable, for the remaining assessment questions.

### **Intensity**

The intensity or severity of pain is often obtained in a numeric format such as on a scale from 0 to 10. Zero is considered to be having no pain and 10 is considered to be the worst pain possible. Be sure to tell the patient the scaling information each time you are rating the intensity of their pain. This is because they might not have ever been informed about this scale before, they may have forgotten what the values represent, or they may have recent cognitive changes that have affected their ability to remember pain scale values. If the patient is deemed to have severe cognitive impairment, then another alternative form of pain intensity rating will have to be used. Always re-state the numerical rating back to the patient once they give it to you for clarification. A follow-up to this rating would be to evaluate whether this value is higher or lower than their usual pain intensity at that pain site.

### **Quality**

The quality of pain refers to a description about what the patient's pain feels like. What kind of pain is it? Is it sharp or dull? Is it aching or squeezing? Does the pain stay in that one location or does it seem to spread out or radiate to nearby areas? This rating can be very helpful in understanding the type of pain involved (somatic, visceral, or neuropathic) and initiating the most effective pharmacological intervention for that specific type of pain.

### **Duration**

It is important to understand how long the patient has experienced this pain and whether it is a new pain. Is this pain always present or is it intermittent? The nurse needs to evaluate how long the patient has been dealing with this pain in terms of hours, days, weeks, months or years.

### **Aggravating factors**

Part of a thorough pain assessment always involves understanding any factors that bring about the pain or make the pain worse? Is there something that the patient does that precipitates the pain?

### **Alleviating factors**

In addition to understanding what brings on the pain, it is also as important to understand what helps to alleviate the pain. This could include medications, positioning, or even a lack of movement. Of those alleviating factors, if any, how long do they last before the pain returns?

### **Current pain regimen**

In the clinical setting, asking about the patient's current pain regimen is often forgotten. Nurses and clinicians are very good at asking about the intensity and duration of pain but often never evaluate exactly what the patient is using to manage the pain. Although the patient's medical record and medication record may be available to the nurse, it is very important to actually ask the patient (or family) what the patient is actually taking for pain and how often. They may have several medications listed for pain in their medical record

that are ordered on an as needed basis. In the inpatient setting, the nurse will have the good fortune of having documentation as to when the last dose was administered and how often they have been getting each medication. In the home or clinic setting, this may not be the case. Just because a medication is ordered every 2 hours as needed, it does not mean the patient is actually taking it every 2 hours. Also, the opposite holds true in that a medication may be ordered for every 8 hours but the patient has been taking it every 6 hours. This is invaluable information that is often overlooked and could be the crucial key in providing adequate pain management for the patient. It could show the nurse if the patient is under or over medicated and if a change in dosing or schedule may be warranted. Refer to Table 6.1 for examples of questions the nurse could ask for each component of the pain assessment.

Table 6.1 Components of a Comprehensive Pain Assessment

<i>Components of Pain Assessment</i>	<i>Sample Question</i>
Current Presence of Pain	Do you have any pain or discomfort anywhere right now?
Usual Pain Experience	What is your usual level of pain like?
	Could you tell me what your usual pain is like on a typical day?
	How do you normally deal with the pain you experience?
Location of Pain	Tell me all the places in your body that you have any pain, discomfort or soreness right now.
	Have you had pain in that location before or is this a new pain?
	If it is a new pain, how does it compare with your previous pain?
Intensity/Severity of Pain	On a scale of 0 to 10, with 0 being no pain at all and 10 being the worst possible pain, what number is your current pain level? (You will need to have patient rate their pain at each location, if multiple areas identified.)
	Is this number higher or lower than your usual pain experience at that location?
	Have you ever had this level of pain before or is this the worst it's ever been?
Quality of Pain	What words would you use to describe the kind of pain you are feeling?
	Is your pain sharp, dull, throbbing, aching, cramping, burning, shooting, squeezing?
	Does the pain stay in that one spot (site or sites patient identified) or does it seem to spread or radiate to other areas too?
Duration of Pain	When did this pain begin? (Ask for each location of pain.)
	If you have had this kind of pain before, how long does it usually last?
	Is your pain always there or does it ever completely go away?
	If it goes away, for how long?

	How long have you been living with this pain? (Days, weeks, months or years)
	Does this pain seem to come and go?
Aggravating Factors	Is there anything that you do that seems to start your pain?
	What kinds of things make your pain worse?
Alleviating Factors	Is there anything that you do that seems to make your pain go away?
	What kinds of things make your pain get better?
Current Pain Regimen/ Last Dose	What are you using to help your pain recently?
	Are you taking medications for pain? (Ask about prescription and over the counter medications.)
	Are you doing other things to help relieve your pain? (Heat, ice, positioning, etc.)
Patients Concerns about Pain	Is there anything else you'd like to tell me about your pain that we haven't talked about yet?

### Pharmacological Interventions for Pain

As you may be aware from any courses you have already taken that focused on pharmacology, there could be an entire book devoted to discussing the latest pharmacological interventions for pain management. While there are many books already written about this topic, we will focus specifically on a general overview of the most widely used medications for pain management. There are many algorithms that our physician colleagues use to calculate proper medication dosage, and since prescribing medications is not within the scope of practice for the registered nurse, we will focus on gaining an understanding about the most commonly used classes of medications for the various types and severity of pain and our specific role in the continual evaluation of the patient's response to these pharmacological interventions. In 1990, the World Health Organization (WHO) first developed a three-step ladder for cancer pain in adults. This approach has been widely cited and used to help clinicians determine analgesic selection for patients with cancer. It includes the administration of certain classes of analgesics in a specific order based on the patient's pain level. The first step of the ladder includes non-opioid medications, plus an adjuvant medication if appropriate. Acetaminophen or NSAIDs are examples that would be used during this first step of the ladder. The next step on the ladder for increasing mild to moderate pain are mild opioid medications, plus a non-opioid and/or adjuvant medication if applicable. An example of this is use of codeine, plus a non-opioid and/or adjuvant medication if applica-

ble. Lastly, the third and final step on the WHO ladder is the use of strong opioid medications, such as morphine, also with or without the non-opioid and/or adjuvant medication if applicable. Often, patients who are living with pain related to a terminal illness have more than one pain medication. Breakthrough pain is pain that occurs in between a patient's usual dosing schedule. The use of a second pain medication on an as needed (PRN) basis for this type of pain can help provide additional relief of pain for patients who have breakthrough pain. Next, we will discuss some key points associated with the various classes of medications commonly used for pain management at the end of life.

### **Non-steroidal anti-inflammatory drugs (NSAIDs)**

NSAIDs are widely used because they affect the inflammatory process. They are commonly used for mild type pain and used as an adjuvant medication, along with an opioid, to manage bone pain in cancer patients. The most common adverse effect from this class of medications are prolonging bleeding times and gastrointestinal problems such as ulcerations in the lining of the stomach. The elderly and those with previous renal problems are more prone to devastating effects from NSAIDs. NSAIDs do have a ceiling effect, which means that there is a maximum dosage that should not be exceeded, as no added analgesia will occur beyond those recommended levels.

### **Opioids**

Opioid medications are typically used to manage pain in patients nearing the end of life. Opioids provide comfort and relief for not only pain, but other symptoms such as dyspnea or breathlessness. Opioids bind to receptors in the brain to help prevent the release of pain transmission to neuroreceptors (Coyle & Layman-Goldstein, 2001). Further classified, opioids can be divided into sub-categories based on the specific receptor they bind to. These include: pure agonists, agonist-antagonists, and pure antagonists (Paice, 2010). Morphine is among the most well known opioid medications and can be quite effective in managing moderate to severe pain. It is commonly used for symptom management for patients nearing the end of life to provide relief from pain and breathlessness. Morphine is cost-effective, as it has been on the market for a long time. On Table 6.2 you will find a list of some commonly used opioid medications.

Table 6.2 Commonly Used Opioid Medications

Codeine
Fentanyl
Hydrocodone
Hydromorphone
Levorphanol
Methadone
Morphine
Oxycodone
Tramadol

### Side effects of opioids

There are several side effects that can be anticipated with the use of an opioid medication. These include sedation, constipation, nausea and vomiting, pruritus, myoclonus, and respiratory depression. Nursing interventions include teaching the patient and family about the effects and side effects of these medications. Sedation commonly occurs with the initiation of an opioid medication but usually subsides after forty eight hours. If sedation persists, the opioid dose may have to be adjusted and/or a stimulant medication ordered to counter the effects. Constipation is by far the most common side effect related to opioid use in patients and can cause a great deal of distress if not proactively managed from the initiation of the opioid. Nurses should instruct patients to incorporate a bowel regimen into their plan of care using prophylactic laxatives and stool softeners. Patients should also be encouraged to increase their fluid intake. Nausea and vomiting is another common side effect that can be managed with incorporation of an anti-emetic medication. Pruritus, or itching, is most commonly found with morphine specifically (Paice, 2010), but can occur with any of the opioids. Antihistamines can help manage this side effect. Myoclonus, or uncontrolled muscle twitching or jerking, occurs most often in patients using higher doses of opioid medications and opioid rotation may be recommended to counter this effect. In cases where opioid rotation is contraindicated, the use of Clonazepam may help to alleviate symptoms. Lastly, respiratory depression is a well known and feared side effect of opioid medications, particularly with morphine; however, it has been found to be less of an issue in patients who are opioid tolerant (Paice, 2010). Often respiratory depression in these patients results from the underlying advanced disease. Naloxone is the medication used to reverse the effects of opioids when respiratory depression is suspected.

### **Additional information about opioids**

Opioid rotation occurs when the currently prescribed opioid is not effective or is causing too many adverse effects. Opioid rotation is when the patient is prescribed a different type of opioid medication. Often patients will have to switch opioids from time to time and the principle of equivalent dosing (or equianalgesia) is the process of calculating the correct dose as a patient transfers from one opioid medication to another. The numeric doses of opioid medications vary and 10 mg of morphine is not necessarily the same as 10 mg of fentanyl, so careful calculation of an equivalent dose in the new medication is done to ensure that the patient is neither under nor overmedicated with the new opioid. Lastly, an effective pain regimen usually includes more than one medication used for pain. This is particularly true in patients with cancer who suffer from both constant and breakthrough pain. Patients will usually receive a long-acting medication that they take twice daily, along with a short-acting opioid used for breakthrough pain and prescribed more frequently, such as every 2–4 hours. As a nurse caring for these patients, it is especially important to assess their response to their medication regimen. If the patient is taking their breakthrough medication at each available time interval and they are still reporting pain, then the patient's long-acting medication may need to be adjusted.

### **Adjuvant Medications**

Adjuvant medications are medications that are used alongside analgesics to provide additional comfort. Although most of these medications are not considered analgesics, they can help to reduce pain caused by other conditions (Paice, 2010).

#### **Corticosteroids**

Corticosteroids are commonly used to reduce tumor size and edema, particularly in patients with cancer. In addition to providing additional pain reduction, steroidal medications such as Dexamethasone have been found to improve both mood and appetite in patients. Nurses should instruct patients to try to avoid taking late doses of this medication, as it may cause insomnia and affect the patient's normal sleep pattern (ELNEC, 2010).

#### **Antidepressants**

Tricyclic antidepressants such as Nortriptyline have also been effective in helping to reduce pain through the inhibition of norepinephrine and serotonin (ELNEC, 2010). They can be very useful, particularly for patients who suffer from neuropathic pain conditions. Nurses should educate patients to anticipate the side effects of sedation, constipation, and dry mouth with these medications.

#### **Anticonvulsants**

Newer anticonvulsants, such as gabapentin and pregabalin, have been successfully used to help reduce neuropathic pain.

### **Non-Pharmacological Interventions for Pain**

There are several non-pharmacological interventions that can be used to manage pain.

Most often than not, patients will use a combination of both pharmacological and non-pharmacological interventions to maximize comfort. Some common non-pharmacological therapies include: cognitive behavioral techniques, physical measures, and complementary therapies (ELNEC, 2010). Cognitive behavioral interventions can include guided imagery, relaxation, hypnosis and distraction. Physical measures include the use of heat or cold, massage, acupuncture, and aromatherapy. Therapies that influence the energy fields of the body, such as Reiki or therapeutic touch, have also been used. Music and art therapy have also emerged as beneficial ways to help reduce the pain experience in some patients, and can be instituted and reimbursed for patients who are receiving the hospice benefit.

### Barriers to Adequate Pain Management

There has been much written in the literature about the various barriers associated with adequate pain management. Barriers can be multi-faceted and include patient-related, provider-related and system-related factors. The concerns and fears surrounding addiction and adverse effects, particularly with opioid medications, are patient-related barriers which present some of the greatest challenges. As a hospice nurse, this topic has by far been the most questioned by patients and families alike. Patients fear becoming addicted to their pain medication, and families who administer opioid medications fear that it could potentially cause respiratory depression. We will discuss some of the ethical dilemmas surrounding hastening death and giving that “final dose” in Chapter 8 on ethics. The best advice for student and novice nurses on this topic is to provide the patient and family with the most recent evidence-based information. The nurse can educate them on the differences between dependence, tolerance, and addiction. Addiction (or psychological dependence) has been found to rarely occur in patients who are using opioids as pain management for cancer or other advanced illnesses. While it is true that physical tolerance can occur, this is a common effect of using any medication, not just opioids. It is most commonly experienced after abrupt withdrawal of the opioid, and can be accompanied by real physiological symptoms such as sweating, nausea, and dizziness. If no longer warranted, careful and slow withdrawal of the medication helps to counteract these symptoms.

Provider-related barriers can also negatively affect adequate pain management as well. Care providers may be afraid of contributing to side effects, tolerance, and even death in patients. Providers are especially cautious in prescribing opioids for the elderly, children, or in patients with a history of substance abuse. This has contributed to poor pain management within these populations. Improvements in pain education have been helpful in the recent decade, but more work is needed to help improve this barrier. Improvements in pain assessment skills, regulation of controlled substances, and pain management strategies are warranted (ELNEC, 2010).

Lastly, health care system barriers include a variety of issues from geography to reimbursement. Patients living in rural areas often do not have access to pain specialists or do not have local pharmacies which carry a wide range of pain medications. Often pain management is

not a top priority within healthcare institutions, and reimbursement mechanisms for pain specialists and pain clinics, as well as palliative care services, are often lacking.

### Symptoms at the End of Life

While pain has been the most widely recognized and researched symptom experienced by those nearing the end of life, it is not the only adverse symptom that patients can experience. A terminal illness can impact any part of the patient's body and the disease can wreak havoc on any of the available body systems. While certain diseases seem to affect certain parts of the body, there are some general symptoms which are commonly experienced by most patients who are nearing the end of life. In this next section we will identify and describe several of the most commonly experienced symptoms patients can have as they near the end of life and the most widely used interventions used to manage them. Additionally, we will more closely examine two symptoms that can cause a great deal of distress: refractory dyspnea and terminal restlessness.

#### Dyspnea/Refractory Dyspnea

Dyspnea, also referred to as shortness of breath or breathlessness, can be a disabling symptom in patients nearing the end of life and can cause more distress and suffering than other types of pain. Patients with dyspnea have said that they would much prefer to have pain than the constant feeling that they cannot get enough air. When some illnesses become advanced or end-stage, dyspnea becomes refractory, meaning that the underlying cause cannot be reversed and the focus of care must shift to interventions aimed at palliating the symptom (Abernathy et al., 2003). Since the causes of dyspnea can be multidimensional, effective management of this symptom can pose challenges for clinicians. In addition to the physical sensation of not being able to get enough air, dyspnea can contribute to anxiety, depression, fear and panic. Dyspnea has been found in patients diagnosed with some cancers, including lung and esophageal, heart failure and COPD.

In order to best manage this symptom, nurses have to complete a thorough assessment of the respiratory system and patients' self-reported dyspnea intensity score. Using a scale similar to the common pain intensity 0 through 10 scale, patients should be asked about their reported rating of dyspnea. Additionally, nurses should use the "assess, document, re-assess, and advocate" strategy described by Lowey and colleagues (2013). As with pain, it is important to conduct a thorough assessment, document your findings, re-assess whether your interventions are effective, and continue to advocate for the patient as needed in order to facilitate pharmacological interventions on the part of the physician.

Management for refractory dyspnea includes treating the underlying cause, if possible, and then opting for palliative measures. Opioid medications are considered to be the gold standard pharmacological treatment for the palliation of dyspnea in patients with advanced illnesses (Lanken et al, 2008). In a recent narrative review examining the effectiveness of opioids for palliation of dyspnea, significant reductions in dyspnea intensity scores were

reported in 80% of the studies included in the analysis (Lowey, Xue, & Powers, 2013). Clinically significant reductions in patients' reported dyspnea scores occurred even in studies that failed to achieve statistical significance. This is known as the minimal clinically important difference (MCID) which has been found to differ between patients with chronic versus acute breathlessness (Oxberry, Bland, Clark, Cleland & Johnson, 2003).

There has also been some research conducted that suggested the use of benzodiazepines to be effective in reducing dyspnea intensity (Navigante, Castro & Cerchietti, 2010). The addition of oxygen to manage refractory dyspnea is inconclusive. If the oxygen saturation levels are within normal range, then oxygen administration should have minimal effects on dyspnea intensity scores. However, some patients report the additional air helps them to catch their breath. Use of a cool fan, pursed lip breathing, and sitting upright slightly hunched over have also been used as nursing interventions that can help reduce dyspnea intensity in patients, but no large scale research has been conducted to evaluate their effectiveness.

### Cough

Cough can be a troubling symptom for patients diagnosed with illnesses such as COPD and lung cancer, heart failure, pulmonary fibrosis and cystic fibrosis. Additionally, in patients with cancer, a cough can result from cancer related treatments, such as radiation therapy (Dudgeon, 2010). Sometimes, hemoptysis (blood in the sputum) can occur from frequent and poorly managed coughing episodes. Antitussive and opioid medications, particularly codeine, have been found to be effective interventions for this symptom.

### Nausea & Vomiting

Multiple receptors in the brain are responsible for the development of nausea in patients with advanced illnesses. Therefore, antiemetic medications target to block these receptors. This symptom occurs in over 50% of patients with advanced cancer, often from the cancer itself and sometimes secondary to cancer treatment (King & Tarcatu, 2010). The causes can be multi-factorial stemming from both the central nervous and/or gastrointestinal systems. The management plan for this symptom should include: assessment, identification of the causes, selecting an anti-emetic and the route of administration, changing protocol if not effective, considering the addition of steroids or antacids, decreasing or rotating opioid medication, and considering the role of anxiety in contributing to nausea (King & Tarcatu, 2010).

There are various classes of antiemetics, but the most common medications used are: Prochlorperazine, Metoclopramide, Haloperidol, Dronabinol, and Diphenhydramine. Depending on the patient's vomiting status, medications may need to be ordered rectally or transdermally, if available. Nursing interventions for the patient with nausea and vomiting include education about various self-care activities and nutrition/hydration. Patients should be advised to eat small, bland meals that are either cold or at room temperature. Care should

be given to avoid odors in the patient's surroundings, including those usually thought to be pleasant. A cool breeze using a fan or open window may also help with nausea.

### Constipation

As mentioned previously with pain management, constipation can be a common and distressing symptom associated with patients nearing the end of life. Although the use of opioid medications is the largest contributor to this problem, changes in a patient's nutritional, hydration, or activity levels can also precipitate constipation. Patients may experience pain or cramping with this symptom and also intermittent periods of loose stools. Laxatives and stool softeners are typically part of the patient's bowel regimen with this symptom. Additionally, sometimes enemas need to be incorporated as well. There are also some herbal teas and drinks that can help keep patients regular, but be cautious with advising these unless approved by the physician. Educate the patient on their individual bowel regimen both verbally and in writing.

### Anorexia & Cachexia

A patient's lack of desire to eat and reduced or non-existent appetite often accompany advanced illness. Anorexia is defined as a loss of appetite with reduced caloric intake. Cachexia is often the outcome of anorexia and is defined as wasting away from lack of adequate nutrition (ELNEC, 2010). Weight loss is present in both anorexia and cachexia and is rarely reversible if it is the result of advanced illness in patients nearing the end of life. Families who have loved ones suffering from anorexia or cachexia often inquire about the use of more aggressive nutritional interventions, such as artificial nutrition or hydration. Depending on the individual patient's diagnosis and prognosis, these options can be explored. More often than not, artificial nutrition and hydration may be contraindicated as it could result in nausea, vomiting, increased edema or dyspnea.

Nursing interventions are to support patient and family and provide education on the benefits and burdens associated with each individual patient. Family members feel badly about seeing their loved ones fade away and not eat and nurses should help provide emotional support and help families understand the symbolism associated with mealtimes. Patients should be encouraged to eat their favorite foods and family members should be encouraged to serve the patient smaller sized portions, so they do not become overwhelmed by the volume of food on their plate. Appetite stimulants, such as Megestrol, may also be used to help boost patients' appetite.

### Fatigue

Fatigue is commonly associated with several advanced illnesses including cancer, heart disease, and advanced renal disease (ELNEC, 2010). It is defined as a subjective and multidimensional experience of exhaustion (Anderson, Dean & Piech, 2010). Fatigue can negatively affect quality of life, but can also be difficult to manage. Often there are several factors contributing to fatigue including both physiological and psychological. A thorough

assessment will include questions about the onset, duration and impact of fatigue on the patient's life, as well as evaluating vital signs, including oxygenation level, thyroid function and hemoglobin levels (ELNEC, 2010). Nursing interventions can include educating the patient about non-pharmacological measures such as energy conservation techniques, physical or occupational therapies, and assistance with the activities of daily living.

### Dysphagia

Dysphasia is defined as "difficulty swallowing food or liquids" (Dahlin, Kurash-Cohen & Goldsmith, 2010) and is found to accompany several illnesses including cancers of the head, neck, esophagus and brain, amyotrophic lateral sclerosis, Parkinson's disease, multiple sclerosis, and dementia. Dysphasia in patients with dementia is very prevalent and has been found to be a causative factor in development of aspiration pneumonia among this population (Dahlin, Kurash-Cohen & Goldsmith, 2010). General debility, medications, and inflammatory disorders have been found to be the most common causes of dysphasia.

Dysphasia is also present in patients who are nearing the end of life, and difficulty swallowing or inability to swallow is found in the majority of patients where death is imminent. Nursing interventions for these patients and their family include education on providing good oral care to keep mucous membranes moist and to provide comfort. Additionally, nurses will need to evaluate the patient's medications, and changes in route of administration may be necessary if the patient is no longer able to swallow.

### Seizures

Patients with primary brain cancers or with metastasis to the brain are at risk for developing seizures as they near the end of life. Seizure management is focused on treatment of the underlying cause if possible, prevention with medications, and implementation of seizure safety precautions. In patients where death is imminent, seizures can be very distressing to the family, and alternative routes for administration of the patient's anticonvulsant medications may be warranted.

### Lymphadema

Lymphadema is chronic swelling as a result of abnormal accumulation of lymphatic fluid. Unmanaged lymphadema can lead to more serious complications including cellulitis, infections, septicemia, and elephantiasis (ELNEC, 2010). It is most commonly seen in patients who have undergone some lymph node dissection during surgical removal of a malignant tumor, or as a result of radiation treatment for cancer. Nursing interventions include educating the patient on monitoring skin integrity, refraining from using affected area (if limb) from auscultation of blood pressure or blood draws, and use of compression garments (ELNEC, 2010).

### Depression & Anxiety

Anxiety and depression are two symptoms that can be found in patients with serious illnesses. Often, the nature of all the factors that coincide with their terminal diagnosis can

result in psycho-social issues and emotional turmoil. The stresses associated with the diagnosis and treatment for serious illnesses can lead some patients to develop anxiety and depression. Sometimes the medical illness itself can contribute or exacerbate anxiety or depression. The losses associated with their illness, such as functional abilities or social status (not being able to work any longer) impact their sense of identity. Many times, these patients feel as if their entire world has been turned upside down and things will never be the same.

Patients who have been informed of poor prognosis or limited life expectancy can be at more risk for development of anxiety and depression. As discussed in Chapter 3, patients may go through periods of depression and grief as they work through the stages of death. Sometimes, patients will need to have extra supports in place, whether they are pharmacological or non-pharmacological, during this time. The patient's previous coping mechanisms, social support networks, and symptoms associated with their terminal condition can all contribute to how they handle these stressors (Pasacreta, Minarik, Nield-Anderson, 2010).

It is important for nurses to assess patients who may be at risk for, or who are exhibiting signs and symptoms of, anxiety or depression. Just because a patient is dying does not mean that they are at less risk for suicide, and nurses should continue to assess for suicide risk in these patients. Nursing interventions for patients suffering from anxiety or depression can include the use of both pharmacological and non-pharmacological measures. Common medications used for anxiety include the benzodiazepines and some anti-depressants. Selective serotonin reuptake inhibitors and serotonin/norepinephrine reuptake inhibitors have been found to be effective to help manage depression. Psychotherapy can be an effective non-pharmacological intervention that can be used in conjunction with medication management (Pasacreta, Minarik, Nield-Anderson, 2010).

### Terminal Restlessness/Delirium

Delirium is a common disorder which is frequently under-diagnosed and poorly managed (Heidrich & English, 2010). There has been much in the literature regarding this disorder in the elderly and its differentiation with dementia. One possible reason that delirium is under-diagnosed may be because it is commonly mistaken for dementia in the elderly. The hallmark difference between delirium and dementia is that delirium has a very abrupt onset with changes in consciousness, cognition, and fluctuation throughout the day (Heidrich & English, 2010). In patients nearing death, delirium has been found to occur in nearly 90% of patients and has been termed "terminal delirium" or "terminal restlessness" (ELNEC, 2010). Medications have been found to be the most common reversible causes of delirium, and thorough evaluation of the patient's medication regimen should be the initial step in determining delirium etiology. Often, in patients nearing the end of life, metabolic or endocrine disturbances are the cause and may not be reversible in patients with advanced disease. In

some patients, unfinished business or spiritual distress can also contribute to terminal restlessness or delirium.

Nursing interventions for patients with terminal delirium or restlessness include supportive care and support for the family. This symptom can be especially troubling for family members to witness in their loved one. Caring for a patient who has terminal restlessness can be difficult and time consuming, especially if there is a risk to the patient's safety, such as falling out of bed. Nurses should assist getting the patient and family any additional services they qualify for, such as home health aide service, which can help the family with some of the care. Educating the family about providing a quiet and peaceful environment may be helpful to help ease symptoms in the patient. Aromatherapy using lavender or sandalwood has provided a calming effect in some patients (Heidrich & English, 2010). Pharmacological management includes the use of Haloperidol as the primary medication used to treat this symptom. Benzodiazepines such as Lorazepam may also be used, but often seem to have a worsening effect, particularly in elderly patients. Risperidone may also be given, but often is contraindicated in patients with hypotension.

Sometimes, patients nearing the end of life will have "nearing death awareness." This was identified by Callanan & Kelley (1992) in their book about hospice patients entitled *Final Gifts*. Sometimes mistakenly confused with components of delirium or hallucinations, many patients nearing the end of life will describe having seen their deceased loved ones in their room or talking about a place they have visited in their dreams. Some patients are very concrete in that they tell you that their death is near while others persist that they have to go or travel somewhere. Most of the time, patients describe these occurrences as peaceful and happy.

### What You Should Know

- Fears surrounding the inadequate management of pain and other symptoms at the end of life are among the top concerns of patients who are dying.
- A comprehensive pain assessment includes evaluating the location, duration, quality of pain, usual pain experience, and alleviating/aggravating factors.
- Refractory dyspnea and terminal restlessness are distressing symptoms in patients nearing the end of life and require a proactive approach to their management.

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## Management of Emotional and Spiritual Distress

“

The pain of the mind is worse than the pain of the body.

-Publilius Syrus

### Learning Objectives

- Explore the meaning of hope in the context of death and dying.
- Describe loss and emotional suffering in the patient who is dying.
- Identify common causes of, and interventions for, spiritual distress in patients nearing the end of life.

While much of the focus of end-of-life care is on the assessment and management of physical pain and symptoms, emotional and spiritual distress can also be experienced by patients who are dying. Yet this type of pain is less frequently discussed and in turn, less apt to be evaluated by the nurse or clinician. Chapter 12 is exclusively focused on grief and bereavement which is more related to the bereaved family following the death of their loved ones. Patients who are nearing the end of life also feel loss and grief, but in a different sense than their family. The purpose of this chapter is to discuss the various emotional and spiritual pain and distress experienced by dying patients and how nurses and clinicians can help support them during their final journey.

### Hope in the Context of Death and Dying

Hope can be an important factor for patients who are nearing the end of life because it is what gives people the determination and will to go on (LaPorte Matzo, 2001). People might not be aware that patients who are dying continue to have hope; however, that hope

might be very different from what they may have hoped for in the past. When a patient first becomes sick and diagnosed with a serious illness, they might hope to be completely cured. As that patient's illness progresses to a point in which it is considered terminal, the patient's hope may change. Instead of hoping for a cure, the patient now may hope for more time or less pain. Whatever they hope for, it is important that the nurse support the patient in their hopes, even if not quite realistic in light of their illness (LaPorte Matzo, 2001). Hope has been found to be a positive and "powerful force against despair" and "can help patients and families journey through difficult times leading up to death" (Zerwekh, 2006).

The concept of hope was described in a study of patients with cancer while deciding about resuscitation status. Twelve out of 23 patients discussed the nature of hope in regard to both present and future decisions. Hope was a way for dying patients to connect to others (Elliott & Olver, 2007). Another study found high levels of hope with the majority of patients, 70% of whom were classified as having very advanced disease (Felder, 2004). Variability in responses was found in another study that explored the relationship of hope and the need for prognostic information in patients with COPD and cancer. Some patients thought that knowing prognostic information might impact their hope and have negative psychological consequences such as increased anxiety (Curtis, Engelberg, Young, Vig, Reinke, & Wenrich et al., 2008). Patients' hope was not differentiated by type of diagnosis.

Nurses can help to foster and promote hope in patients by encouraging them to live in the present and focus less on the future (Zerwekh, 2006). This can help assist the patient to evolve their original hope for a cure into hope for other things, such as hoping to have well-managed symptoms, hoping to feel well enough to spend quality time with family and friends, and hoping to accomplish any goals they have before their death. Ersek (2001) outlined 6 nursing interventions that could foster hope (Table 7.1).

Table 7.1 Nursing Interventions to Promote Hope

Keep symptoms well managed.
Encourage involvement in positive experiences that transcend their current situation.
Foster spiritual processes and find meaning.
Promote reconciliation and connections with others.
Assist patient in setting realistic goals.
Focus the patient's attention on the short-term future.

### Loss and Emotional Suffering

Loss is defined as the "absence of a possession or future possession" (ELNEC, 2010) and occurs when something or someone is missing (Zerwekh, 2006). Loss can refer to a person, relationship, thing, or situation, and can occur well before a patient dies. The patient

and family can have feelings of loss as they anticipate the impending losses that will occur or the death itself (ELNEC, 2010). Grief is the emotional response to a loss, which will be discussed in the context of the family in Chapter 12. Patients can have a series of losses related to their illness, well before they get close to the end of life. In a study that examined the perspectives of patients with end stage heart failure or COPD, patients reported having multiple losses throughout their illness trajectory (Lowey, Norton, Quinn, & Quill, 2013). Some of these included the loss of functional abilities and independence as their illness worsened, and most feared the losses that were to come. This anticipatory loss can greatly impact emotional status and precipitate suffering in patients. Patients who live with advanced illnesses often feel trapped in many ways by their illness. As mentioned with the study above, patients feel as if they are losing themselves and their abilities a little bit at a time, and that can take a terrible toll on their emotions. If left unmanaged, this can cause a great deal of suffering.

Suffering is defined as “a state of severe distress associated with events that threaten the intactness of a person” (Cassell, 1991). Suffering can impact a person’s body, mind, or spirit and is greatly compounded with the presence of pain. It can be acute or chronic, and a patient living with serious illness can experience either kind or both together (Zerwekh, 2006). The Hospice and Palliative Nurses Association defines existential distress or suffering as “suffering that is not relieved by treatment of psychological symptoms or that occurs in the absence of physical symptoms” (Hospice and Palliative Nurses Association, 2012). Existential suffering is related to who we are as individuals and can threaten a patient’s sense of identity. In a recent article that explored existential suffering a typology of 8 factors were found to be related to this kind of distress. These include: death anxiety, loss and change, freedom of choice, dignity of the self, fundamental aloneness, altered quality of relationships, meaning, and mystery (Kissane, 2012). The last factor, mystery, relates to the mystery about what happens to people after they die. This question is even considered by the most faithful of people and is a normal response of being a human being. In essence, not being entirely certain where a person will go after they die can cause a great deal of stress and anxiety, which contributes to suffering. This factor is closely related to a particular kind of suffering that originates from spiritual distress, which we will discuss next.

### Spiritual Distress

Spirituality has been defined as “more of a journey and religion may be the transport to help us in our journey” (Narayansamy, 2004). Patients who are dying often think about their own spirituality. For some, it is a time to become more in touch with one’s spirituality, and for others it is a time for their spirituality to become even stronger. Still, there are patients who do not want to discuss spiritual issues and are often angry at their situation and angry at any higher powers which they feel responsible for their impending death. As a nurse who cares for patients nearing the end of their lives, spirituality is something that needs to be taken into consideration. It can be just as important for a patient as their unmanaged pain

or dyspnea and needs to be treated as a priority by nurses. Often nurses are uncomfortable with asking about or talking with patients about spiritual issues, particularly if the nurse is not a religious or spiritual person. As mentioned before, a person can be spiritual without being part of a formal or organized religion. In hospice and palliative care nursing, issues related to spirituality and religion are frequently encountered, and most nurses are comfortable addressing these with their patients. There are many instances in which hospice nurses work closely with chaplains and clergy in the care planning of patients. It is also not uncommon for hospice nurses to pray with their patients. The extent to which a nurse prays with patients is largely dependent on the comfort level of the nurse with an expression of religiosity in the form of prayer.

The nurse should assess the patient's emotional and spiritual needs and concerns during each interaction or visit. There are several formal instruments available to measure hope and hopelessness and the nurse should check with their facility to see which ones are available for use. It is also helpful for the nurse to ask the patient whether they would like to have a chaplain or minister come to talk with them. Sometimes patients will want to talk with someone but are either not comfortable about it or are not aware of who to ask about it.

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## Ethical Concerns in End-of-Life Care

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In the sick room, ten cents' worth of human understanding equals ten dollars' worth of medical science.

-Martin H. Fischer

### Learning Objectives

- Define ethics and the role of ethics in medical decision making.
- Identify basic ethical principles and concepts.
- Examine difficult decisions in end-of-life care.

### Ethics in Medical Decision Making

Ethics is a branch of philosophy that is focused on understanding the moral principles of people and how they make decisions based on what is considered morally right or wrong (Merriam-Webster, 2014). There are often ethical issues that can arise in the context of end-of-life care, particularly when patients and families make decisions regarding the care they will accept or not accept. As nurses, sometimes our morals and values are in conflict with those that our patients have, and this can cause some distress for the nurse. By having an understanding about some of the issues that can arise during end of life decisions, the nursing student or novice nurse can be better prepared for what to expect and how best to handle ethical issues.

As discussed in Chapter 5, patients' goals of care are what patients place highest value on and would hope to achieve in regard to their illness. These goals are based on the patient's moral principles and values. These are the goals the patient wishes for in terms of their illness. Often as patients near the end of life, many difficult decisions will have to be made. Some of

these are related to what kinds of medical treatments they would want to have if they were no longer able to make their own decisions. In the clinical setting, it is not uncommon to witness conflicts between the patient's wishes and those of their family. Sometimes, there can be conflicts between what the clinicians believe to be best for the patient and what the patient and family want to have done. Other times, the insurance or health care system has specific criteria that may come in conflict with the goals and values of the patient or family. This was evident in the recent national news story about 13-year old Jahi McMath (Fox News, 2013). In this case, the family wanted to continue to keep their young daughter on life support which conflicted with what the health care facility wanted. After several evaluations, the child was determined to be medically brain dead, and therefore continuation of medical treatments was considered to be futile. The goal of this chapter is to provide a basic understanding about ethical principles and to explore issues surrounding the issues that can arise during end of life decisions in patients who are nearing the end of life.

### Basic Ethical Principles and Concepts

Nurses need to possess a basic understanding about the scope of practice and standards of care. This can be found in the *Standards of Professional Nursing Practice* from the American Nurse Association (ANA, 2010). Additionally, nurses should refer to the *Code of Ethics for Nurses with Interpretive Statements* (ANA, 2015). These resources should assist the nurse with their expected behaviors and role within the professional discipline of nursing.

Autonomy, beneficence, nonmaleficence, and justice are four of the basic ethical principles used to guide nurses and clinicians in the care and decision making of patients. Many of these same standards apply for nurses who are involved in clinical research as they are a way to ensure that people's rights are protected as guided by specific moral principles.

#### Respect for autonomy

This principle is described as an agreement to respect another's right to self-determine a course of action and to support another's independent decision making (ANA, 2015). Sometimes it can be difficult to see a patient make a decision about their health that the nurse does not personally agree with or that the nurse does not feel is the best decision for that patient's individual circumstances. As nurses, we must support and advocate for our patients' rights, including their right to make decisions. While a nurse might not agree with a patient's decision, they must support it. For example, a nurse has been caring for an elderly gentleman for several months as he has been receiving treatment for cancer. This patient has decided to stop his cancer treatments and focus on spending time enjoying his family for the time he has left. While the nurse has grown fond of this patient and would not want him to die, they must respect the patient's wishes and choices for his own medical care.

#### Beneficence

Beneficence is the principle of "doing good" and has been suggested as having four distinct parts. These include:

- Not to inflict evil or harm.
- To prevent evil or harm.
- To remove evil or harm.
- To do good or promote good.

(Kennedy Swartz, 2001)

Sometimes it might be difficult to differentiate between doing good and doing no harm, which is nonmaleficence, because it is often easier to determine what is clearly bad or harmful more than what might be good or a benefit. Kennedy Swartz recommended that there is a greater obligation to not cause harm than there is to do something that might benefit the patient. Nurses should keep that in mind when assisting patients with difficult decisions.

### Nonmaleficence

Nonmaleficence is the principle of refraining from causing unnecessary harm. Although some of the interventions that patients receive might cause pain or some harm, nonmaleficence refers to the moral justification behind why the harm is caused. Sometimes harm may be caused to a patient in order to prevent them from further harm. If the act is for a greater good for the patient and is not meant to deliberately harm them, it is justifiable. An example of this is the all too common clinical situation that occurs in end-of-life care. A patient whose death is imminent is in pain and requires pain medication to maintain comfort. The patient is very close to death with irregular respirations around 8 breaths per minute. The nurse needs to administer the pain medication but fears that giving it may hasten (or accelerate) death. According to the Code of Ethics for Nurses (ANA, 2015), the nurse may “not act deliberately to terminate life”; however, the nurse has a moral obligation to provide interventions “to relieve symptoms in dying patients even if the intervention might hasten death.”

### Justice

Justice is the principle that governs social fairness. It involves determining whether someone should receive or is entitled to receive a resource. The Code of Ethics for Nurses (ANA, 2015) states that nurses’ commitment is to patients regardless of their “social or economic status.” In healthcare, sometimes the benefits must be balanced with the burdens to determine who is eligible to receive some type of care. As mentioned in the beginning of this chapter, medical futility is continuing to provide a medical intervention or treatment that would not provide a cure or benefit to the patient. As with the young Jahi McMath, who was determined to have brain death, continuing to keep her alive on life support would be futile, as there is little or no hope for recovery. So this decision was considered just, as discontinuation of life support was not based on her age, ethnicity or socio-economic status. It was based on her medical diagnosis.

Some additional terms that accompany ethical principles include informed consent and capacity. Informed consent respects a patient’s autonomy and enables him/her to make an

informed decision based on factual and accurate information. If a patient is not informed that declining to have a needed surgery would result in his death, then they cannot make an informed decision. If once this information is disclosed and the patient decides not to elect the surgery, it is an informed choice based on the facts. Capacity refers to the ability of a patient to understand information and to make choices or consent to care. So using the same example about whether or not to have a life-saving surgery, if the patient was cognitively impaired because he had Alzheimer's disease, he would not have the decisional capacity to make an informed choice. If he was cognitively intact and decided not to elect surgery, then that would be his right.

### Difficult Decisions in End-of-life care

Caring for patients who are nearing or at the end of life often enables nurses to bear witness to the complicated and difficult decisions that patients and families must make surrounding many sensitive issues. Although nurses have their own morals, values, and beliefs, they sometimes do not correspond with the patients' values, beliefs, or wishes, and an internal conflict for the nurse can ensue. Some of the medical treatments and decisions we will discuss are simple and others are more complex. Regardless of the intervention or treatment, the nurse should focus on helping the patient weigh the benefits and burdens of the intervention, rather than focus on the intervention itself (Kennedy Swartz, 2001). Now we will discuss some of the difficult decisions that patients often need to make in end-of-life care.

#### Withholding/withdrawing of medical interventions

One of the dilemmas that can occur relates to the cessation of medical interventions in patients. Sometimes these interventions range from minor, such as a non-life sustaining medication, to more complex, such as mechanical ventilation. The rationale for stopping these interventions is often based on the fact that the burdens are outweighing any benefits the patient may get from it. Sometimes life-sustaining therapies may prolong suffering at the cost of decreasing the patient's quality of life. Patients and their family often decide to stop medical interventions based on some of these factors. One of the most heart-wrenching decisions that family members often have to make is about withdrawing life sustaining treatments (life support) from patients. This is why advance directives are so important. Advance directives are documents that enable patients to make their decisions about medical care known to their family and health care providers, in the event that they are unable to make those decisions themselves (National Cancer Institute, 2013). If a family member knows for sure that their loved one would not have wanted a particular medical intervention done, it may help to alleviate some of the burden they may feel about making the decision. It also helps prevent the initiation of some life sustaining treatments beforehand, in which case no decision will be need to be made to withdraw that intervention. It also can help reduce overall costs of futile medical care (Coyne, Smith, & Lyckholm, 2010).

#### Do not attempt resuscitation (DNAR)

In 2005, the American Heart Association has changed from the more recognized acronym

for do not resuscitate (DNR) to DNAR (Breault, 2011); however, depending on the location, the more traditional DNR terminology may still be used. If a patient has an order for a DNR or DNAR, it means that the patient has elected for cardiopulmonary resuscitation (CPR) to not be initiated or administered in the event of a cardiac arrest. CPR could include the use of chest compressions, cardiac drugs, and the placement of a breathing tube. Electing to have or not to have CPR is a difficult but common medical decision that patients nearing the end of life often make. The success rate of CPR has been low, around 18%, among all hospitalized patients who arrest over the past 50 years (Berry & Griffie, 2010), and it is well known that the percentage is even lower among patients with advanced illnesses such as terminal cancer or end stage heart failure. A “do not intubate” (DNI) order often accompanies a DNR order, which states that the patient elects not to be intubated with a breathing tube if they go into cardiac arrest. Chest compressions and the use of cardiac medications could still be used.

#### **Allow natural death (AND)**

Allow natural death is a more recent terminology some health care institutions have adopted to use instead of the traditional DNR orders. Whereas a DNR order states that no attempts should be made to start CPR in a patient, an AND order states that only comfort measures are taken to manage symptoms related to comfort. An AND order simply allows the patient to remain comfortable while not interfering with the natural dying process.

#### **Medical order for life sustaining treatment (MOLST)**

Sometimes also referred to as physician order to life-sustaining treatment (POLST), these newer forms of advance directives were developed in order to improve the communication of a patient’s wishes about life-sustaining treatments among healthcare providers and settings. It is currently in use in 26 states across the United States (Polst Organization, 2014).

#### **Hastening death (Principle of double effect)**

The principle of “double effect” refers to some decisions that clinicians have that will produce both desirable and undesirable effects (ELNEC, 2010). The example given earlier for non-maleficence, in which the nurse administers a pain medication in order to alleviate a patient’s pain and suffering but this same intervention may also contribute to a hastened death, is also an example of “double effect.” The medication will reduce the pain but also further reduce the patient’s respiratory rate to a level that is inconsistent with life. In the case of double effect, the nurse or clinician should always consider what the intended effect of the intervention is. Is the pain medication being administered to reduce pain and suffering, or is it being given to further reduce the patient’s respirations?

#### **Terminal/palliative sedation**

Terminal sedation (more recently called “palliative sedation”) is an intervention used in patients at the end of life, usually as a last effort to relieve suffering (Knight & Espinosa, 2010). It involves sedating the patient to a point in which refractory symptoms are con-

trolled. The goal is to control symptoms, and the patient is sedated to varying degrees of consciousness to achieve this. The intent is not to cause or hasten death, but rather to relieve suffering that has not responded to any other means. Often the patient is sedated to a point at which they are unconscious. Table 8.1 shows the four criteria required for a patient to be considered for palliative sedation.

Table 8.1 Criteria Required for Palliative Sedation

Patient has a terminal illness
Severe symptoms present are not responsive to treatment and intolerable to patient
A “do not resuscitate” order is in effect
Death is imminent (hours to days)

(Knight & Espinosa, 2010)

The fourth criteria is the most difficult to determine; however, one study found that the mean time between initiation of terminal sedation and death ranged from 1.9 to 3.2 days (Fainsinger et al., 2000). Terminal sedation has been compared with slow euthanasia and assisted dying; however, they are not the same thing. The key difference is based on the intent or purpose of the intervention. The intent is not to hasten death but to relieve suffering that cannot be relieved by any other available method. In assisted dying or physician assisted euthanasia, the intent is to produce death in order to relieve suffering. Palliative sedation has been supported as a means to alleviate suffering by the United States Supreme Court, and the Hospice and Palliative Nurses Association is in favor of its use (Hospice and Palliative Nurses Association, 2003).

### Assisted dying

Assisted dying is defined as “an action in which an individual’s death is intentionally hastened by the administration of a drug or other lethal substance” (Volker, 2010). Under this general definition, there are two distinct subcategories that include assisted suicide and active euthanasia. In assisted suicide, the patient is provided with the means to carry out suicide, such as providing a lethal dose of a medication. In active euthanasia, someone other than the patient is the one who carries out the action that ends the patient’s life (Volker, 2010). In the United States there are four states that have laws allowing assisted dying. The state of Oregon was the first to pass the Death with Dignity Act in 1997, and since then, Washington, Vermont, and New Mexico have followed suit (Volker, 2010). The vast majority of ethical codes from the main nurses’ organizations prohibit the involvement of a nurse in the assisted dying of patients. The Oregon Nurses Association issued a statement that grants nurses the right to refuse involvement in the care of a patient who has elected assisted suicide.

### What You Should Know

- Nurses caring for patients at the end of life have a moral and professional obligation to follow the guidelines depicted in their professional and ethical standards.
- The absence of an advance directive can make end of life decision-making difficult for families of dying patients who are no longer able to speak for themselves.
- Nurses need to advocate to ensure that their patients' goals of care are met while following ethical principles.

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## Care at the Time of Death

“

What we have done for ourselves alone dies with us; what we have done for others and the world remains and is immortal.

-Albert Pike

### Learning Objectives

- To understand the role of the nurse during the dying process and death.
- Describe the phases and associated signs/symptoms involved in the dying process.
- Explain various nursing interventions to facilitate a good death.

Dying is a process. It involves the cessation of physical, psychological, social and spiritual life here on earth. What happens beyond death is unknown to those reading this book. Typically, before a person dies, there is a cascade of events that are collectively known as the dying process. The dying process is the transition that a person goes through that ultimately ends in death. Each person's dying process and death is individual to that person. Dying is an individualized experience and each person dies in their own way and time (ELNEC, 2010). Patients who know that they are dying will usually make their wishes known about where they want to spend their final days and hours. It is vital that the nurse involved in that patient's care advocate for the patient's wishes for their end of life.

Every nurse has an obligation to facilitate their patient's wishes regarding their care preferences at the end of life. As nurses, we cannot with 100% certainty ensure that each of our patient's dying process will go smoothly without any problems. Advanced illnesses and

diseases that are terminal differ in the way they progress from person to person. An intervention that works well for one person dying of cancer might not work for another person. What we can do is to be armed with the best knowledge about management of symptoms during the dying process and utilize them appropriately as needed. It is the goal of this book that all nurses regardless of practice setting will be informed about the best nursing care practices at the end of life. This is so we can facilitate a “good death” for our patients, remembering that a good death means ensuring that patients’ preferences are met and symptoms are managed through the use of open communication.

One of the most important things we can do for patients who are dying is to provide the best possible care for them and their families during the last phase of life through death. This is particularly important during the “imminent” phase. This is the phase that precedes the actual death, and is also the time when the patient typically loses consciousness. The care the nurse provides during this phase will affect the family’s memories of their loved one’s final days and hours on earth. It is vital that the nurse performs thorough assessments, rapid response to changes in status, rapid titration of medications, and timely discontinuation and introduction of interventions aimed to promote comfort.

There are many characteristics associated with the dying process which nurses who care for patients who are dying have grown accustomed to. The sights and sounds that can occur during that time, while normal for the nurse and clinician, can be extremely frightening and distressing for the family. One of the most important things that a nurse can do who is caring for patients nearing the end of life is to provide care for the family during this time and remember that although you may not remember what care you provided, the family will remember every second that took place during that time. If there are things that they witnessed that were distressful, that could negatively impact the perception of their loved one’s death. If their concerns were addressed and the patient was kept as comfortable as possible, that will positively impact the perception of their loved one’s death.

## Phases of Dying

### Actively dying

According to ELNEC (2010), there are two typical roads to death that can occur during the actively dying process: the usual road or the difficult road. The usual road is the best we can hope for when caring for persons at the end of life. It begins with sedation and lethargy and progresses to a comatose state and then death. The difficult road includes restlessness and confusion that often progresses to unpleasant hallucinations and delirium. Myoclonus and seizures can also accompany the difficult road.

Physical signs and symptoms associated with both roads can accompany the patient months, weeks, days or hours before death and vary from person to person. Refer to Figure 9.1 for a list of physical signs that the actively dying patient commonly exhibits.

Figure 9.1 Signs and Symptoms during Active Dying

Pain
Dyspnea
Fatigue
Cough
Bowel Changes (Constipation/Diarrhea)
Incontinence
Anorexia/Cachexia
Nausea & Vomiting
Depression/Anxiety
Seizures

Depending on the patient's goals for care, various treatments are available to manage these conditions. Refer to Chapter 6 for a description of the best interventions used to manage the signs and symptoms patients are afflicted with during the end of life. The role of the nurse during the active dying phase is to support the patient and family by educating them on what they might expect to happen during this time, addressing their questions and concerns honestly, being an active listener, and providing emotional support and guidance.

### Transitioning

Transitioning is a term used by clinicians to describe the period of time in between the actively dying phase and the imminent phase. In this phase, patients begin to withdraw from the physical world around them in preparation for their final journey. Some examples of this could include: decreased interest in activities of life, less frequent and shorter interactions with others, and acknowledgement of the presence of people and things that are not visible by clinicians and caregivers. This is referred to as "nearing death awareness" and often documented by clinicians as "hallucinations." Possible explanations of this phenomenon from the medical community are as a result of hypoxia, acidosis, or alterations in metabolic processes. Patients will generally not exhibit any signs or symptoms of distress with this awareness, whereas patients whose dying is taking the difficult road might show signs of distress or agitation with their awareness.

During transitioning, it is important to keep the patient's area as comfortable and peaceful as possible. Common lights and noises can contribute to restlessness and agitation; therefore

it is advisable to keep lights soft, shades closed if possible, and external noises limited to a minimum.

### Imminent

The term imminent is defined as “about to happen, forthcoming or near” (Merriam-Webster, 2012). The patient has transitioned into this last phase of the dying process and death can occur at any point now. Not all individuals will present with every sign or symptom, and the symptoms will occur in no particular order. During this phase, the body is in the process of shutting down. Multi-system organ failure often occurs and will result in some typical symptoms (Table 9.2).

Table 9.2 Signs and Symptoms of Imminent Death

<i>System</i>	<i>Symptom</i>
Cardiological/ Circulatory	Cool and clammy skin
	Mottled extremities
	Rapid or irregular pulse
Musculoskeletal	Inability to ambulate
	Inability to move/turn in bed
Neurological	Increased lethargy
	More difficulty to arouse
	Confusion
	Restlessness
Respiratory	Increased respiratory rate
	Periods of apnea or Cheyne-Stokes respiration pattern
	Inability to cough or clear secretions
	Presence of increased secretions (“death rattle”)
Urinary	Decreased and/or dark urine output

Often the change of care will focus as death becomes imminent (Berrie & Griffie, 2010). The assessment of vital signs will cease unless requested by the family, at which point the nurse would gently explain the overall rationale for measuring vital signs and whether this would provide any benefit for the patient. Out of all the stages of the dying process, this last

phase is the one in which impending death becomes a reality for everyone involved. The family knows that their loved one will die; however, it is usually not as evident as it can be until death becomes imminent. During this phase, the patient becomes unresponsive to those around them and may appear to be sleeping. Sometimes the patient's eyes will be partially open as they are resting. In hospice, we believe that the patient can still hear or sense the activity and loved ones around them and so we teach families to continue to talk to and gently touch their loved ones.

The interaction between the patient and their family during the imminent phase is very individual. Some families are distant and uncomfortable being near their loved one during this phase. No one wants to see their loved one in that state; it hurts to watch, and can be too painful for some to cope with. Even though the family may know death is imminent, it will not feel real until they are actually seeing it. Other families may be very involved with the patient during this phase: lying in bed with their loved one, talking to them, and being present in the moment. Neither scenario is wrong, and the nurse caring for patients at the end of life needs to always remember that. The nurse should support the patient and family, reserve judgment, and not make assumptions about the reasons behind the family's behavior. The nurses' role is not to be the authority on how the family should act, but to provide comfort and quality of life for the patient and empathetic support to the family.

There are often several nursing interventions and activities for the nurse to perform during the imminent phase. Most of which are related to the communication, coordination and continual assessment and response to changes in patient's status. When the death is imminent, the family must be informed that death is near. As mentioned before, sometimes this is shocking to the family, despite knowing that their loved one is dying. This has to be communicated to the family in a sensitive and calm manner. Each nurse will have their own way to exchange this information, but it is very important that the family be told that death can occur at any time so that they can prepare. There may be family in the area or out of town that would like to come and see the patient and who is waiting until the patient gets closer to death. It is important to educate families during the dying process that the final phase may progress very quickly as a way to encourage loved ones to come sooner rather than later.

The imminent phase is also the time when some families may want clergy or pastoral care present. Depending on their religious affiliation, some patients and families may want sacraments or special blessings performed before death occurs. It is important to tell the family that the process leading to death has begun, and that if they would like clergy present they should begin that process now. The nurse can assist families with obtaining pastoral care if the family does not have their own. The coordination of spiritual support may be extremely important to the family at this time and the nurse should be sure to evaluate for this as part of their assessment.

## The Death

There are two ways that death can be classified: clinical death and biological death. Clinical death comes first and is when a person's heart stops beating. Circulation of the blood and respiration also stops once there is a cessation of heart beat. It is during this time that individuals can be revived by way of CPR. Oxygen can be given, the blood can be kept circulated and the heart beat could be potentially restored. Most patients who are at the end of life opt for a do-not-resuscitate order, and therefore CPR is rarely given. Research has found that CPR is ineffective at restoring heartbeat in patients who are living with terminal illness (ELNEC, 2010). There is a 4 to 6 minute window in which patients can be revived with CPR. Without CPR, in approximately 4–6 minutes after clinical death (the cessation of heart beat), brain cells will begin to die from lack of oxygen. This is called biological death and is called the point of no return, meaning that once the brain dies, CPR will not be able to bring that person back. It is at this time that the cells in other organs, such as kidneys or eyes, will also begin to die. Several hours after biological death occurs, rigor mortis occurs. Rigor mortis is defined as the temporary rigidity of muscles occurring after death (Merriam Webster, 2014). It results from the loss of adenosine triphosphate (ATP) which makes muscles become stiff with the loss of energy flow (Bate-Smith & Bendall, 1947). Rigor mortis will begin to set in several hours following death and be at its peak 12–18 hours following death. Rigor mortis will disappear 48 hours following death.

CPR is not typically performed with patients who are expected to die and those who have a DNR, DNAR, or AND. Witnessing a patient's death without the resuscitation process can be difficult for the nurse or clinician, as we have been trained to do everything possible *not* to cause or contribute to a patient's death. In end-of-life care, the death is the expected outcome of the care we provide, and as nurses we want to ensure that the patient has as "good" a death as possible and that they have died in the manner they wished. But it is very difficult to stand by and observe a death in progress—everyone silent with eyes fixed on the patient's chest. As mentioned before, respirations can become quite erratic, very shallow with extended periods of apnea in between breaths. The moment will come in which the patient's chest will not rise again. This time period can seem like an eternity for both the family and the nurse. Take extreme caution when determining whether or not the last breath has been taken. Extended periods of apnea close to death can last up to a minute or more. Be certain that death has occurred before proceeding to assess for signs of life. Typically the patient's mandible will drop and almost a sudden pallor will appear. The pulse in the carotid artery may still be palpable, although very faint and thready, until the heart catches up with the absent respirations. This may take a minute or two. Be sure to listen for a heartbeat with a stethoscope for a full minute. In hospice this is performed for two reasons: to ensure that the patient has died, and also to provide the family with the extra peace of mind knowing that their loved one is really gone. Never fail to assess for signs of life, including heartbeat, respirations, and pupil status by checking the patient's pupils with a light for fixation and dilation. The nurse should make sure that the patient is covered with a

light sheet up to below the shoulders. It is atypical for the deceased patient to be completely covered including face and head, so refrain from doing so unless otherwise directed by the family.

Following the death of a patient, the nurse should offer their condolences to the family and extend assistance with contacting any other family members or individuals the family requests. Depending on the location of the death, the nurse would contact the medical examiner to notify them of the death, as well as the physician and other clinicians who were involved with the patient. The nurse can also contact the funeral home for the family as requested. In home care, the nurse would ask the family if it was alright to remove any tubes or catheters from the patient, and if they would like to assist in bathing/preparing the patient for transport to the funeral home. The nurse would assist the family in removing any jewelry or other items from the patient. Be sure to maintain the highest dignity and respect for the deceased patient during this post-mortem care.

### What You Should Know

- Dying is a multi-faceted process that is uniquely individual to each person.
- The most common signs and symptoms before death include: increased pulse/respiratory rate, Cheyne-Stokes respirations, cool/mottled skin, and decreased urine output.
- It is important to provide support for the patient and family throughout the entire dying process.
- Be sure to communicate to the family when a patient's death becomes imminent so that other family members and/or clergy can be called.

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## Nurse–Patient–Family Communication

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The most important thing in communication is hearing what isn't said.

-Peter Drucker

### Learning Objectives

- Identify several ways nurses can engage in more effective communication with patients and families.
- Describe some basic communication skills nurses can use to enhance communication.
- Identify several follow-up responses to use with patients.

As mentioned several times throughout this book, the importance of good communication between the nurse and patient/family cannot be overstated. Communication has been found to be a central part of the nurse–patient relationship and is based on the formation of trust and personal attitudes (Lowey, 2008). Most students, and even novice nurses, think that if they are not performing an actual skill for a patient, they are not performing effective and important nursing care. However, there is so much good that nurses can do by simply communicating with patients. Communication does not refer to the general pleasantries that people engage in as a formality. Casual conversation might be useful to get to know a person; however, is not what denotes effective nurse–patient communication. There are several ways that that nurses can engage in more effective communication with patients and families. Some of these will be described in this chapter, as well as some basic tools that

can be used by nursing students and novice nurses as ways to help train them to engage in more effective communication with patients and families. Since communication is one of the skills that nursing students feel the least comfortable with, we will explore some possible follow-up responses that can be used with patients.

While the same response may not be appropriate for every patient, there are some effective responses nurses can use to clarify meaning or elicit further information from patients. This is particularly important because patient communication can often be unclear.

Sometimes, the more subtle statements that patients make require active listening and good communication on the part of the nurse in order to really understand the needs or concerns of the patient.

### **Be Yourself**

Chances are that most of the nurse or clinician students who are reading this book are nice people. Anyone who willingly enters into a profession like nursing or healthcare is probably a caring person. However, the student may not always be themselves when interacting with patients. This persona is used as a way to keep the “invisible boundary” between themselves and patients as they have been trained. This professionalism is necessary and required; however, there is a way to be yourself while maintaining professional boundaries.

This can be a difficult thing for students and novice nurses to understand. How can I be myself and still maintain a professional demeanor and boundary? It is something that takes trial and error and also some comfort with oneself and with the profession. If a patient asks you an innocent question such as “Do you have any children?” or “Have you lived around town all your life?” There is no adverse reason for not answering, unless the nurse is uncomfortable in the situation. Most nurses engage in honest, casual conversations with patients and families, and it helps patients to get to know the nurse and vice versa. It also helps put patients more at ease with you. The special nurse-patient connection formed as a result is important in fostering trust, which encourages the patient to follow through on the various things you will teach them as part of good nursing care. Patients may be sick but they are not unintelligent and they can sense if the nurse is not being himself or herself. In end-of-life care, an effective nurse-patient relationship is very important and can be successfully fostered as a result of simply being oneself.

### **Be Honest**

Good nursing care also involves being honest with the patient and family. If the nurse is asked a question that they do not know, a good response would be to honestly tell the patient that you do not know but will get the correct answer for them — and be sure to follow through and actually do that. Patients who have spent a lot of time in the health care system have encountered many individuals along the way, as well as a wide variety in the levels of care provided. It is never acceptable to lie to a patient when asked a question

related to their health that is within your scope of practice to disclose. This is important for the novice nurse to understand. Nurses are rarely the clinicians to “break the news” or give prognostic information to a patient for the first time. That is the role of the provider, and if a patient asks you about this, you need to defer them to the provider. You should not ignore their questions, because any question the patient has is valid to them. The nurse needs to follow-up and find the correct person to provide that information to the patient.

If a patient who already has been told prognostic information makes a statement to the nurse such as “So I’m dying, aren’t I?” This is an opportunity to be honest with the patient and establish effective nurse–patient communication. Since they have already been told their prognosis, and the nurse has first confirmed this to be true, the patient can be responded to in an honest way such as “I know that the doctor has told you a lot of difficult information recently, and I am really sorry to hear about that.” This is a good initial response to their question, without seeming insensitive by simply repeating the prognosis. Then, listen to their response and take it from there. This is where the novice nurse may find it difficult to know how to respond. By being honest and oneself, the nurse is halfway there, despite not knowing exactly what to say. Nurses should never respond in a cliché matter-of-fact way when it comes to death and dying. Statements such as “Well, we are all dying slowly each day anyway” minimize the concerns of the patient. Nurses want to show patients that they are fully engaged with them and are genuinely interested in their concerns.

### Be Genuine

So far we have talked about being yourself and being honest; two important qualities to foster effective nurse–patient communication. What is the difference between being honest and being genuine? Being genuine is somewhat related to being oneself, as long as you are not an overly sarcastic person, which might hinder an effective nurse–patient relationship. To be genuine is to be actual, real or true; sincere and honest (Merriam–Webster, 2014). To be authentic is to be real, to show devotion is to show that you honestly care about the person, and to be sincere is to be free from dishonesty. The nurse should possess all these qualities in their interaction with patients, because if the patient believes the nurse is authentic, devoted, and sincere, they will be more apt to engage with the nurse.

### Show That You Care

The best ways to show patients that you care is to be polite, be respectful and follow through. Nurses should use some level of formality when addressing patients. Since many patients will likely be from an older generation, they are accustomed to being addressed by their last name, such as Mrs. Smith. From the initial contact with the patient, the nurse should always address them this way unless asked to do otherwise. If the patient invites the nurse to call them by their first name, then it is acceptable to do so.

Make eye contact with patients as a way of showing that you care. If the nurse’s face is

focused on the computer or medical record more than the patient, it does not show them that you care. Maintain good eye contact, smile, and show that you are happy to be their nurse. This is sometimes difficult to do; nurses are people too, and can have bad days or issues that make them feel unhappy. It is important for the nurse to put those aside while in the presence of the patient. Be mindful of nonverbal communication. A lot can be said by nonverbal cues, such as body language. Having an open disposition can help show patients that the nurse cares. If possible, try to be at eye level with the patient, rather than standing over them. That helps to level the power between you and make the patient feel more like an equal in engagement. It also doesn't hurt to use physical touch; shake the person's hand when you meet them or touch them lightly on the arm or shoulder.

### Follow Through

Lastly, be sure to follow through with anything that needs to be done after your contact with the patient. During your next encounter with the patient, provide the answer or the item that the patient requested, and this will help to show the patient that they are cared about. This is especially important because it shows that the nurse listened to their concerns or questions and remembered to act on them.

### The Family

All of the aforementioned skills can also help the nurse engage more effectively with the family members. It is important to not leave the family members out of the conversation. Include them in your greeting and your "small talk," and maintain eye contact with them as well as the patient. A patient who feels that their family is being listened to and respected will be a more effective partner in communication. And a family who sees that their loved one is being listened to and respected will be more likely to communicate with the nurse.

### Common Follow-up Responses

Effective communication between the patient and the nurse requires some skills on the part of the nurse. These skills are infrequently talked about in nursing school and even more infrequently practiced. But they are as essential as being able to maintain a sterile field, decipher lab values, or read an electrocardiogram. When communicating with a patient or family, the nurse should be mindful of how they respond to the patient or family. Every patient or family interaction is different and there is no "one size fits all" approach that can be used. However, there are some ways that nurses can respond to patients that can show the patient that their concerns are valid and are being heard. Table 10.1 contains some key phrases that the novice nurse should learn to take the place of certain other phrases that do not foster effective nurse-patient communication. As you can see, the original response denotes negativity whereas the suggested response seems more open to the patient's concerns.

Table 10.1 Suggested General Responses

<i>Original Response</i>	<i>Suggested Response</i>
I don't know.	I don't know, but I will find out for you.
I can't do that.	Here is what I can do for you.
That's too bad.	I'm sorry that this is happening to you.
I can't tell you that information.	I will find out who can help get that information for you.
Why don't you relax?	I understand why you are so upset and I'm sorry.
I wish there was something I could do.	What can I do for you? How can I help you?
I'm too busy right now.	I will be there to help you in a moment.
No problem.	I am glad I could help.
Don't worry about it.	I understand your concerns; what can I do to help?
It's good for you.	This is important because it will help you get better.

These are just a few examples showing how adding a few different words can make a big difference in the way the nurse responds to the patient. Most of the suggested responses show an underlying focus on the patient. Instead of the response being about what the nurse *cannot* do for the patient, it's about what the nurse *can* do. This helps improve any potential anxiety, fear, or anger that the patient may be having and instead makes the patient feel that their concerns or statements have been heard and are important. In the current healthcare system, this is one of the frequent complaints that patients express on post-discharge satisfaction surveys. That is why so many changes in clinical practices surrounding communication have been instituted in the last decade. Nearly every hospital room now has some type of dry erase board or method for the patient to refer to that communicates who their nurse is, what day it is, what tests they may be having that day and so on. Something like this seems so simple, and yet it can make a great difference in the overall experience of the patient. Being mindful of how the nurse responds to a patient or family member can also impact the experience of the patient. Communication among the nurse, patient, and family is such an important part of the care delivered by nurses with all patients, but it is especially important for those who are nearing the end of life.

### What You Should Know

- To develop a strong nurse–patient relationship, some of the most important factors required for good communication are to be yourself, be honest, be genuine, show that you care, and follow through. Do not forget the importance of including the family in communicating with the patient.
- Remember to focus your responses to the patient about what you *can* do versus what you are not able to do for them.

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## **PART III**

# **Afterwards**



## Diversity in Dying: Death across Cultures

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Whether it is seen in personal terms or trans-personal terms, whether it is Heaven or Nirvana or Happy Hunting Ground or the Garden of Paradise, the weight and authority of tradition maintains that death is just an alteration in our state of consciousness, and that the quality of our continued existence in the afterlife depends on the quality of our living here and now.

-John Smith

### Learning Objectives

- Identify the role of the nurse in providing culturally competent care to patients nearing the end of life.
- Examine the basic components of funeral traditions in the United States.
- Describe beliefs and traditions associated with death and dying among various religions and cultures.

Cultural competence is a term that nurses have learned is a necessary part of providing good nursing care to patients. The population of the United States is becoming more diverse, and nurses should be both knowledgeable and comfortable providing care to a diverse range of patients. Diversity includes issues related to a person's ethnicity, sexual orientation, age, gender, and socio-economic class (ELNEC, 2010). Nurses who care for patients nearing the end of life should have a good understanding about the various beliefs and traditions held by various cultures about death and dying. This is something that is not always thought of

in nursing school, but it is essential information to know when caring for patients who are dying.

The role of the nurse in end-of-life care includes providing care that is individualized and culturally competent for each patient. As mentioned before, the care that is provided to patients during their final hours will be remembered forever by the family members who were present. If the patient is from an ethnicity or religion that is different from the nurse, it is important to provide care that is respectful and appropriate within that particular faith or cultural tradition. Any nurse who will be caring for a patient whose particular culture differs from theirs is strongly encouraged to take the time to learn some basic information that will help to inform them about that culture and the practices they hold with regard to death and dying.

### Funeral Traditions in the United States

The energy and stamina which young adults who are studying nursing bring to the profession is invaluable; however, life experience with death and dying or funerals is often lacking in younger people. This next section was written to provide the young nursing student or novice nurse, who may not have had any previous experience with attending a funeral service, some basic information about funerals. Although most cultures and religions have their own unique rituals and traditions associated with funeral practices and mourning, we will identify some basic components found in the traditional funeral in the United States.

#### Options for final arrangement: Burial or cremation

One of the reasons that people should discuss their wishes before they become ill is so their family will know what final arrangements they would like to have after they die. Although some believe it is morbid to talk about end of life and funeral wishes while one is young and healthy, it can be a very important conversation to have. The family has had to make many difficult decisions while their loved one was dying, and then, after death, they have to plan the funeral. This is one of the most difficult things that people have to do in their lives. Although most people who die are older, there can be death that occurs in people of all ages, including newborn babies, infants, children, adolescents, and young adults. While the majority of nurses who are reading this book will care for adults or older adults, it is imperative to understand the perspective of the family who are undergoing the planning process.

One of the greatest decisions the family will have to make (unless specified in advance by the patient) is whether their loved one will be buried or cremated. Both methods have been around for thousands of years, and it is really a matter of personal preference (and sometimes family history). When burial is elected, the deceased will be interred in the ground in a cemetery, entombed in a vault in a mausoleum, or, more recently, have a “green burial.” Burials can be expensive; the average median cost of a funeral is over \$8,000. (National Funeral Directors Association, 2012). The deceased will need to have their body prepared

and/or embalmed. Embalming is the process in which the blood is removed from the body via the veins and replaced with an embalming solution via the arteries, usually containing formaldehyde and other chemicals (National Funeral Directors Association, 2012). The body will be prepared cosmetically and dressed before being placed in the casket. Along with the casket, there is usually a vault that is placed into the ground that encompasses the casket. There are also fees associated with the grave or mausoleum space and opening up the ground/vault for internment. The funeral director has a fee for their services and use of the funeral home for visitation. A hearse is the vehicle that transports the deceased from the funeral home to the church (if applicable) and to the cemetery. The family will obtain a death certificate and may write an obituary for the local newspaper. Lastly, if burial is used, often there will be a headstone or marker purchased for the grave.

Although both burial and cremation can be costly, cremation is usually less expensive than a burial. Cremation is the process by which the deceased body is burned into ashes using heat and fire. Any fragments that remain after the procedure, including bones, are ground down to a finer consistency with special tools at the crematorium. When selecting this method, the body does not get embalmed. The body is placed into an approved container, such as a wooden casket, for the cremation. Certified crematoriums have special policies and procedures in place to ensure that the highest quality care and dignity are provided during the cremation process. The remains are placed into a special container called an urn. There are many choices available to families for urn styles as well as caskets. There can still be formal visitation and funeral practices that take place before the deceased is cremated, or a memorial service can be held with the ashes of the deceased after cremation occurs. Cremated remains are then either buried in the ground or mausoleum in a cemetery, kept by the family, scattered in an outdoor location or divided up between family members (although this practice is not used in some religions who believe that the remains of a person should not be divided).

### Visiting hours

Visiting hours, also called visitation or a wake, is when the deceased person's body is prepared and placed on display in a casket. Formal visiting hours are held at the funeral home in which family and friends of the deceased can come and say their final good-byes and offer condolences to the family. Visiting hours usually occur 1-2 days before the funeral or memorial service. Many times there is a formal book that visitors can sign. Flowers and other memorial displays often are part of this time. Many families will display photos or prized possessions of their loved one or have favorite music played in the background. More recently, families are using technology to make video displays of pictures or home videos of their loved one during visitation.

The casket can be open or closed during visiting hours. An open casket is where the deceased body is visible to family and guests; a closed casket means that the deceased body cannot be seen by family or guests. Often if the death resulted from severe trauma, a closed

casket is the preferred method. In certain religions, such as Judaism, deceased are never displayed in an open casket, nor is embalming allowed.

### **The funeral or memorial service**

A funeral is the formal ritual that takes place which is often officiated by clergy from the decedent's religion. This can take place at the funeral home or in a church. The Catholic faith usually has a funeral mass that takes place at a church officiated by the priest. The casket is often closed at church funerals. Sometimes, family or friends of the deceased will speak or give a eulogy about their loved one during the funeral or memorial service. Internment follows the funeral service and a procession of guests usually follow the hearse carrying the casket or remains of the deceased to the cemetery.

### **The burial or internment**

The burial or internment of the deceased can take place right after the funeral or memorial service or at some later date. The clergy will often accompany the deceased and family to the cemetery and provide a small service at the grave. Many times the grave or mausoleum will be blessed as the deceased is interred. If the deceased was a member of the military, a special military service may be conducted at that time. The casket is usually wrapped in the American flag and then given to the decedent's next of kin. In the U.S., gatherings are commonly held following a funeral service in which family and friends gather for a meal.

### **Diversity of Beliefs and Traditions across Religions and Cultures**

Now that we have discussed the basics that comprise the traditional funeral in the United States, we will focus on some more specific practices and traditions from various cultures and religions. Table 11.1 outlines traditions associated with several selected religions.

Table 11.1 Religious Beliefs about Death, Dying and Funerals

<i>Religion</i>	<i>Beliefs pertaining to death</i>	<i>Preparation of the Body</i>	<i>Funeral</i>
Catholic	Beliefs include that the deceased travels from this world into eternal afterlife where the soul can reside in heaven, hell, or purgatory. Sacraments are given to the dying.	Organ donation and autopsy are permitted.	Cremation historically forbidden until 1963. The Vigil occurs the evening before the funeral mass is held. Mass includes Eucharist. If a priest is not available, a deacon can lead funeral services. Rite of committal takes place with interment.
Protestant	Belief in Jesus Christ and the Bible is central, although differences in interpretation exist in the various denominations. Beliefs include an afterlife.	Organ donation and autopsy are permitted.	Cremation or burial is accepted. Funeral can be held in funeral home or in church and led by minister or chaplain.
Jewish	Tradition cherishes life but death itself is not viewed as a tragedy. Views on an afterlife vary with the denomination (Reform, Conservative, or Orthodox).	Autopsy and embalming are forbidden under ordinary circumstances. Open caskets are not permitted.	Funeral held as soon as possible after death. Dark clothing is worn at and after the funeral/burial. It is forbidden to bury the decedent on the Sabbath or festivals. Three mourning periods are held after the burial, with Shiva being the first seven days after burial.
Buddhist	Both a religion and way of life with the goal of enlightenment. Beliefs include that life is a cycle of death and rebirth.	Goal is a peaceful death. Statue of Buddha may be placed at bedside as the person is dying. Organ donation is not permitted. Incense is lit in the room following death.	Family washes and prepares the body. Cremation is preferred but if buried, deceased should be dressed in regular daily clothes instead of fancy clothing. Monks may be present at the funeral and lead the chanting.

Native American	Beliefs vary among tribes. Sickness is thought to mean that one is out of balance with nature. Thought that ancestors can guide the deceased. Believe that death is a journey to another world. Family may or may not be present for death.	Preparation of the body may be done by family. Organ donation generally not preferred.	Most burials are natural or green. Various practices differ with tribe. Among the Navajo, hearing an owl or coyote is a sign of impending death and the casket is left slightly open so the spirit can escape. Navajo and Apache tribes believe that spirits of deceased can haunt the living. The Comanche tribe buries the dead in the place of death or in a cave.
Hindu	Beliefs include reincarnation, where a deceased person returns in the form of another, and Karma.	Organ donation and autopsy are acceptable. Bathing the body daily is necessary. Death and dying must be peaceful. Customary for body to not be left alone until cremated.	Prefer cremation within 24 hours after death. Ashes should be scattered in sacred rivers.
Muslim	Muslims believe in an afterlife and that the body must be quickly buried so that the soul may be freed.	Embalming and cremation are not permitted. Autopsy is permitted for legal or medical reasons only. After death, the body should face Mecca or the East. Body is prepared by a person of the same gender.	Burial takes place as soon as possible. Women and men will sit separately at the funeral. Flowers and excessive mourning are discouraged. Body is usually buried in a shroud and is buried with the head pointing toward Mecca.

(ELNEC, 2010; Health Care Chaplaincy, 2009).

### What You Should Know

- Visiting hours, the funeral, and the burial are the main components in most traditional U.S. funerals.
- Different cultures have varying traditions pertaining to death and when caring for patients belonging to a particular faith or culture, the nurse should become familiar with the traditions the patient and family would like to observe.

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## Grief and Bereavement

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You will lose someone you can't live without, and your heart will be badly broken, and the bad news is that you never completely get over the loss of your beloved. But this is also the good news. They live forever in your broken heart that doesn't seal back up. And you come through. It's like having a broken leg that never heals perfectly—that still hurts when the weather gets cold, but you learn to dance with the limp.

-Anne Lamott

### Learning Objectives

- Identify the main factors associated with grief and bereavement in the patient, family, and the nurse.
- Describe the various types of grief and their associated manifestations.
- Examine the types of support that can assist individuals to live with their loss.

Grief and bereavement are universal experiences that people go through when they are dealing with a loss in their lives. In end-of-life care, nurses must understand the fundamentals about grief, loss, and bereavement on the part of patients and families, and also within themselves. Individuals each express and cope with losses differently and a nurse should expect to see that when working with patients and families at the end of life. According to ELNEC (2010), the role of the nurse includes three things: (1) the nurse must facilitate the grieving process by assessing the grief; (2) the nurse must assist the patient with issues and concerns related to the grief; and (3) the nurse must support the survivors. The purpose of

this chapter is to identify the main components related to grief, bereavement and mourning in the context of end-of-life care, to describe the various types of grief, and to explore the support needed to help individuals cope and live with the loss.

### **What is Grief?**

Grief is a process that can begin long before the loss of a loved one. As mentioned in Chapter 7, the patient and family can have feelings of loss even as they anticipate an impending loss. Grief is the emotional response to that loss. Similar to the stages of dying, individuals go through a process to help them eventually cope and be able to live with that loss. This process has been referred to as “grief work” and as with the stages of dying, people can go through the stages in varying order. People never get over their loss, but find ways to live with the loss and without their deceased loved one (ELNEC, 2010).

A three-stage model of grief was developed by Corless (2010) and includes the following components: notification and shock, experiencing the loss, and reintegration. The first stage, notification and shock, is when the individual first learns or acknowledges the loss. They often feel shock and numbness and may isolate from others during this initial phase. In the second stage, the individual really experiences the loss both emotionally and cognitively. A host of feelings can occur during this stage including; anger, sadness, emptiness, as well as physical manifestations (insomnia, loss of appetite). The final stage is when the individual reorganizes and reintegrates into their life without the person they have lost. This last stage characterizes the healing that should ideally take place at the end of grief.

### **Types of Grief**

There are several different types of grief reactions that people can have. Some of these are considered to be normal while others signify an alteration in coping with the loss.

#### **Normal or uncomplicated grief**

This type of grief symbolizes the most desirable and universal reaction to loss and is considered to be normal Corless (2010). The individual will have physical, emotional, cognitive, and behavioral reactions following the loss and will eventually move toward adjusting to it. The period of time for this can vary from person to person and is dependent on the type of relationship, type of loss and individual factors related to the bereaved. The nurse should support the family to take the time that they need for this normal grief processes to happen.

#### **Anticipatory grief**

Anticipatory grief is grief that occurs before the loss of a loved one. Sometimes anticipatory grief starts at the time of a terminal diagnosis and can proceed until the person dies. Both patients and family members can feel anticipatory loss. For the patient, they can anticipate the loss of independence, function or comfort. This can cause a lot of pain and anxiety if not given the proper support. For the family, they often start grieving for the loss of their loved one before they die. Perhaps it is because they bear witness to the pain or suffering

they see their loved one go through or maybe they are also envisioning their own life without their loved one in it. They start to think about all the things that they still wanted to share with their loved one, who will likely not live long enough to do. This type of grief has been shown to help cushion a person's bereavement reaction (Corless, 2010).

### Complicated grief

Complicated grief may require professional assistance depending on its severity and can be further classified into four different types as shown in Table 12.1. Individuals could be at risk for complicated grief if they experience losses that are sudden or traumatic or resulting from suicide/homicide. If the person has already had recent losses or previous losses from which they did not resolve their grief, it can contribute to developing complicated grief reaction with the new loss. Lack of a support network or concurrent stressors such as ailing health or relationships, also can contribute to this type of grief (ELNEC, 2010).

Table 12.1 Four Types of Complicated Grief

Type	Characterized by
Chronic Grief	Normal grief reactions that continue for an extended period of time.
Delayed Grief	Normal grief reactions which are suppressed or postponed because the survivor avoids the pain of loss (consciously or unconsciously).
Exaggerated Grief	An intense reaction to the loss that can include thoughts of suicide, phobias or nightmares.
Masked Grief	Survivor is not aware that their behaviors are a result of the loss.

(ELNEC, 2010)

### Disenfranchised grief

This type of grief is defined as grief that has not been validated or recognized (ELNEC, 2010). This type of grief often develops in individuals who have lost loved ones to stigmatized illnesses, such as AIDS, or through socially unacceptable ways, such as abortion. The loss of a previously severed relationship, such as with divorce, can also contribute to this type of grief because the individual may not be able to mourn as openly for that loved one due to the circumstances surrounding their relationship.

### Unresolved grief

In this type of grief, the bereaved has failed to move through the stages of grief and accomplish the work needed to come to terms with the loss (Corless, 2010). Many factors can contribute to the manifestation of this type of grieving and can include: lack of formal clo-

sure (loved one's body never found or laid to rest), multiple or concurrent losses, or social isolation.

### Manifestations of Grief

As mentioned before, grief can consist of physical, emotional, cognitive, and behavioral reactions to the loss. The bereaved person can feel the pain from their loss in any or all of these ways. Some of the physical manifestations of grief can include: feeling physically ill from the loss, headaches, heaviness or pressure, tremors, muscle aches, exhaustion and insomnia. Cognitive manifestations can include: inability to concentrate, sense of confusion or disbelief, preoccupation with the deceased, and hallucinatory experiences. Emotional responses include: anxiety, guilt, anger, sadness, feelings of helplessness, and relief. Lastly, behavioral manifestations can include: withdrawal, impaired performance at work or school, avoiding anything that reminds one of the deceased, or possessing constant reminders of the deceased (ELNEC, 2010).

### Bereavement

Bereavement includes grief and mourning and has been considered to be the "time period in which the survivor adjusts to their life without their loved one" (ELNEC, 2010). This period can include the time right after the loss or death occurs, during the funeral proceedings, and during the grieving process afterward. Different individuals respond to this period in various ways. A person's age, physical and emotional health, culture, and previous experience with loss can all affect the way that they grieve during this period of time. Bereavement differs from grief in that it includes the period of time from the beginning of the loss until acceptance has been reached. Mourning takes place during this time and can differ based on personal and cultural factors.

### Letting go

The phrase "letting go" is a concept that has been explored in the context of death and dying. Family members who provide care to a terminally ill loved one often experience the phenomenon of "letting go." This involves a process in which the end result is recognition of their loved one's impending death, with some freedom from the immense emotional constraint usually experienced prior to this awareness. This can be done both before the death and after, and is part of grief and bereavement. Lowey (2008) conducted a concept analysis of "letting go" and found that the concept is comprised of four distinct attributes. These include: (1) a shift in thinking, or a crucial turning point; (2) recognition of the fact that, despite efforts to save the loved one, they are dying (or have died) and all hope for recovery or prolonged life is exhausted; (3) acknowledging the impending physical and emotional loss that will occur with the death; and (4) allowing the progression to inevitable death to occur by choosing not to prolong or impede this natural progression. Some of these attributes are similar and might be compared with anticipatory grief, anticipatory mourning, and death awareness.

## Support for the Bereaved

Both informal and formal support can be utilized to help bereaved individuals cope with the loss of their loved one. The kind of support a person requires will differ and it is important for the nurse to conduct a thorough grief assessment. ELNEC (2010) recommends that assessment of grief occur at regular intervals throughout the course of illness and should ideally begin at diagnosis. Grief should be assessed frequently in the bereavement period in order for the nurse to be able to develop an effective plan to assist the bereaved in coping with their loss. Bereavement follow-up with families is part of most hospice programs and can include formal activities and events to promote closure and acceptance. Many hospices have non-denominational memorial services to honor those patients who have been lost. Family members and staff are invited to participate, and these can be effective at helping both parties find closure. Other formal types of support can include support groups. Most organizations and/or health care systems have various support groups for individuals, some of which are specific to a particular type of illness (i.e., cancer). Individual or group counseling or psychotherapy are other methods that can assist the bereaved in coping with their loss.

Some informal support that can help the bereaved are visits by family and friends, attending informal support groups, or support from members of the bereaved's church. Nurses who continue to be involved with the bereaved following the patient's death should provide support to the survivor to help them "feel the loss, express the loss, and complete the tasks of the grieving process" (ELNEC, 2010, pp M7-7). Nurses are in the ideal position to assist patients with identifying and expressing their feelings related to the loss. One of the biggest facilitators of this process which nurses can engage in is active listening. By actively listening to the bereaved, it helps them express their feelings and feel as though they are being heard. Developing a strong nurse-patient-family relationship in the beginning of the health care encounter can help with the support needed during the bereavement period.

## Support for the Nurse

While this chapter has mainly focused on the family who is grieving the loss of a loved one, it is also important to recognize the health of the nurse who cares for patients at the end of life. Much of what has been written in this text focuses on the importance of establishing an effective nurse-patient-family relationship which will foster effective communication. In Chapter 10, we discussed the various components that can enable the nurse to enter into this type of strong relationship. While these tips will help to make the patient and family feel connected to their nurse, it can also make the nurse feel connected with the patient. In end-of-life care, with each connection will come a subsequent loss as patients die. Over time, multiple losses that are not well-supported could take their toll on the nurse. Nurses witness much pain, suffering, and distress in patients and families alike. They also can experience distress related to ethical or moral issues that are encountered as a result of the various health care decisions that occur at the end of life. Hospice nurses in particular can be

vulnerable to “cumulative loss.” Cumulative loss is when nurses experience multiple successions of losses, often on a daily basis, without adequate time for resolution before the next loss (ELNEC, 2010). Over time, this can lead to emotional distress in the nurse.

Factors that can affect the way nurses who care for dying patients adapt to the losses experienced in the workplace include: nurse’s educational level, personal death history, life changes, and support systems (ELNEC, 2010). Nurses who work with this population have to find a way to balance the losses they experience through healthy expressions of their feelings. In hospice care, nurses usually have formal team debriefing meetings following the death of patients, as well as memorial ceremonies they can attend to help them find closure. These are formal types of support that are available to nurses, depending on their setting. Informal support systems, such as talking with co-workers or peers, can also help provide a supportive environment for the nurse. The nurse may find solace from spiritual or religious services or support from their own clergy. Engaging in self-care activities, such as massage or vacations, can also help the nurse cope with the effects of their role. Finally, nurses who work in end-of-life care should continue to engage in continuing education activities which can help provide knowledge and skills about ways to effectively cope with the effects of their role (ELNEC, 2010).

### What You Should Know

- Grief is the process by which individuals cope with loss.
- Individual factors and circumstances surrounding the loss can affect the grief response and extend or complicate the grief experience.
- Both formal and informal support mechanisms can be effective in helping the bereaved cope with their loss and find closure.

### References

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- End of Life Nursing Education Consortium (2010). *ELNEC – core curriculum training program*. City of Hope and American Association of Colleges of Nursing. Retrieved from <http://www.aacn.nche.edu/ELNEC>
- Lowey, S. E. (2008). Letting go before a death: A concept analysis. *Journal of Advanced Nursing*, 63(2), 208–215.

## Afterword

### Evaluation of Self: Lessons Learned

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Life is not measured by the breaths we take but by the moments that take our breath away.

-Author Unknown

#### Learning Objectives

- Evaluate one's own attitudes and beliefs about death and dying.
- Describe the writer's perspectives about the realm of nursing care at the end of life using lessons learned from clinical experiences.

One of the reasons I decided to write this book was because I wanted to share my knowledge and experiences of end-of-life care with nursing students and novice nurses. The majority of what I have learned throughout my career was learned through experience and the clinical setting. If there was a patient with a diagnosis that was unfamiliar, I would read about it. If there was a new procedure that a patient had undergone, I would research it. If there was a symptom that was not responding to a particular medication, I would explore possible reasons. End-of-life care, by its very nature, enabled me to gain a vast amount of knowledge, not only about various disease states and treatments, but about everything one can imagine is related to concerns and needs of those who are dying. There have been many improvements with medical and palliative interventions for cancer, heart disease, COPD and dementia during the past 15 years that have impacted the progression of end of life nursing care. It has grown in response to all the new research and evidence based practice. This research can show us what is effective in nursing interventions. Additionally, studies that asked patients to describe their experiences with healthcare have spurred further improvements in end of life.

This afterword is presented in question and answer format so the reader can use my own

self-reflections to begin to contemplate what they have read and what it means to them. Self-reflection is essential in providing end-of-life care because the nurse will witness the full circle of human emotions and: happiness, joy, laughter, wisdom, forgiveness, anger, sorrow, pain, silence, and peace.

### **“What made you decide to work with dying patients?”**

Working with patients who were dying was not something I planned on doing when I was in nursing school or even as a new nurse. I wanted very much to save people's lives and restore them back to an optimal state of wellness, not to be beside them as they died. Once my own children were born, I decided to work in home care because the schedule was more flexible. I had several encounters with patients who were living with advanced illnesses and saw firsthand what they went through. Some patients were very open about their illnesses and their own mortality. In homecare, the nurse is in the patient's setting, not vice versa, and many felt more comfortable to talk about their concerns. I liked being able to just talk with patients and make them feel better by just listening to them. I remember visiting a patient who I took care of for several months. This patient wasn't always the most pleasant, as he had been living with some serious health problems and functional limitations. He was angry and depressed most of the time. He was going to be switching over to hospice care, and I remember him telling me about all the things that hospice was going to help him do before he died. He was the happiest I had ever seen him, and it was because of this thing called “hospice.” I didn't know that much about hospice at that time but it intrigued me after seeing this patient's response about it.

As I experienced more and more patients who were afflicted with various illnesses that caused a great deal of pain and suffering, I knew that there was more that I could do to help patients like these. There was an interaction with one particular patient that was the reason I decided to care for patients who were dying. This patient had stage four lung cancer with bone metastasis and I called his physician to request that a pain medication be ordered. The patient had nothing but acetaminophen ordered for pain and his pain was intolerable. I was angry that no one had advocated for this patient before. Why wasn't he already receiving a pain medication? Why didn't his doctor order one for him and why didn't his regular nurse call and get him one sooner? How could anyone let this patient suffer this way? That single event made me decide that my place was to help patients who were nearing the end of life. Soon after that I applied for a job in hospice and palliative home care.

### **“How can you work with patients who are going to die?”**

I cannot recall how often patients, families, and other nurses and clinicians who do not work in hospice ask me this question. How do nurses who work with patients who are dying deal with the difficult things that they encounter? Death is an event that is both dreaded and perceived negatively. People do not like to talk about it, plan for it, or acknowledge its presence, even when it is right there. I suppose that anyone who deals with patients who are dying on a daily basis must at some point become comfortable with their

role. After all, if they weren't, they would not be an effective resource for those who were dying. My response to this question is, "How could I *not* work with these patients?" I feel honored to have been able to share in the end of life journeys with so many patients and their families. It has been a true blessing in my life to be able to really make a difference in the lives of so many people. The special knowledge and great compassion I have for people who have been afflicted with life limiting illnesses has made it possible for me to do this type of work.

As I mentioned before, I feel the need to be an advocate for these patients throughout their journey because there can be many needs and concerns that go unanswered and unnoticed. It baffles me how today, with all the technological advances that have been made in medicine, the basics often become lost. I used to witness that with hospitalized patients when I worked in acute care. Sometimes there would be a new patient on the unit who would not get a meal tray. Was it ordered? Who checked to see what they had eaten, or if they were eating at all? It can be the same way in end-of-life care. There may be a patient with end stage cancer who does not have any pain when they are admitted to hospice. While that is a blessing, those of us who work in the field realize that patients with advanced illnesses can deteriorate quickly. A good nurse or clinician should anticipate what the patient might need after their assessment. In hospice, it is always a good idea to have interventions readily available for management of common end of life symptoms. This can include pain, dyspnea, nausea, incontinence, respiratory secretions and anxiety. In some hospices, there are "hospice kits" which contain limited doses of medications used to treat some of these symptoms; patients receive a kit after admission to home hospice care. I have had my share of patients who have deteriorated quickly and had nothing in the home to quickly manage that symptom. My role was to help get them relief, and after various calls, persistence, and advocacy, I was able to do that for them. The most rewarding part of my job was being able to assess a patient's needs and quickly respond to getting those needs met.

**"Do you ever get sad or cry during or after losing a patient you were very fond of?"**

This question is really a no brainer. How could I not get sad when someone I have gotten to know and cared for has died? That sadness was usually for me, not for that person. I was sad because they were gone and I would not be able to go to their home and help them any longer. When I thought instead about the person who died and all the things they were living with and going through when they were here, I usually felt glad that they were finally at peace and would not have to live that way anymore. For the most part, nurses and clinicians have a good handle on how to deal with their own emotions in the context of caring for others, because of that invisible barrier that nurses are supposed to keep safely in between themselves and their patients. This barrier is not impermeable, though, and nurses can feel sadness and loss after their patient dies.

I have been very good at keeping my composure in the homes of patients who were suf-

fering or who have just died. I go into an automatic “comfort the family and do your job” mode, and that helps to keep myself in check at that time. Later on, I find myself reflecting on the patient and thinking about what they meant to me and the interactions that I had with them. There have been a few rare occasions that I have felt a strong desire to attend a patient’s funeral. As a hospice nurse, this is not possible to do with every patient. There have been a few patients who for one reason or another I had really bonded with, which caused me to seek closure by attending the funeral. Closure is essential for the clinician working in hospice. Exposure to frequent emotional stresses without some way to cope can negatively affect the clinician, which would greatly impact the subsequent care they provide.

**“Do you ever feel that you have lost any nursing skills because you work in hospice?”**

This might seem like a silly question but I have encountered the perception that, once a patient enters hospice, there is nothing to be done for them anymore, and that the nurse loses their nursing skills because of this. I can tell you that I have completed more thorough assessments and administered more interventions as a hospice nurse than I ever did working with non-hospice patients. The rapid progression of the patient’s illness warrants accurate and continual assessment and quick response to changes in status. I personally feel as though I really honed in on my nursing skills when working in hospice. As far as communication skills, hospice is where I developed expertise in these as well. So much of the role is dependent on effective nurse–patient–family communication, and that was an area that developed for me while working in hospice.

I also feel as though working in end-of-life care provided me with continual education in the field. Instead of just being specialized in one disease state, I felt very knowledgeable in many types of illnesses and their various treatments. I became well versed in oncology, cardiac, pulmonary, and neuromuscular illnesses. I also learned a lot about the health care system in general and reimbursement mechanisms. In addition, nurses who work in end-of-life care also learn about family dynamics and how that impacts both the patient and the family during that time. No, I do not feel as though hospice has made me lose anything; in fact, it has only enriched and improved my nursing knowledge and skills.

**“What are some of the most rewarding things about working with hospice patients?”**

Working in hospice has truly been a blessing for me in my life. Hospice nursing has made me be a better person because I have witnessed such courage and persistence in the human spirit. I have seen people live with terrible illnesses that cause a lot of suffering and distress yet they remain pleasant and loving. I have also seen the worst in people and how unmanaged symptoms and complicated grief could tear patients and families apart. These experiences, both good and bad, have helped me to mature and to really see what is important in life. It has helped me to appreciate good health and all that I have in life. It has helped me treat those around me a little better because you never know what the next day holds. It

has helped me become more spiritual and open to the various possibilities that exist for us when we leave this physical world. It has helped me prepare myself for the losses I have had to face in my own life and help me be a better daughter, sister, wife, mother, friend, and nurse. So as you can see, I have reaped many personal benefits and rewards from this type of work.

I also find that working with hospice patients in home health care is even more rewarding because you are invited into a total stranger's home and allowed to be a part of their journey and life for a while. I always feel rewarded to be able to help provide information and teach patients and families about how to manage their illness, to advocate for patients so that they can have what they need to improve their quality of life, and to take part in the little everyday things that mean so much to them during this time in their lives. I remember a patient who could not take an actual shower in her tub for several years due to her health. When I admitted her to home hospice, I evaluated her environment and was able to get her grab bars, a special extended sprayer, and a shower chair so she could get in the shower. I must admit that I got a lot of personal joy out of seeing her so happy to be able to get her hair washed the way she wanted it washed in the shower. It is rewarding to be able to make someone so happy for such little time and work on my part.

Finally, the other most rewarding thing that I feel privileged to be able to do is to provide a family member the peace of mind that their loved one was given excellent nursing care at the end of their lives. Hopefully I have done my job well enough to be able to provide them with quality care that they can reflect on with the last memories they have of their loved one. I feel rewarded to be able to help a patient become comfortable, peaceful and as content as they can be instead of in an environment that is filled with pain, suffering and chaos. Often it is the latter that I find myself walking into when I first meet a patient, and my job is to help transform their environment into a place where they can have a dignified and peaceful death.

### What You Should Know

“If you were a patient who was dying, what would you want from your nurse?”

I would want a nurse that would advocate for me until I had my concerns and needs met. I would want a nurse who cared enough to reflect and care about his/her own self. I would want a nurse who allowed me to vent and cry without responding to me with clichés and minimalizing my concerns. I would want a nurse who was honest and didn't pretend to know what my new medication was if she really never heard of it before. I would want a nurse who didn't make my family feel as though they were bothering them when they called to tell the nurse about a problem I was having. I

would want a nurse who enjoyed their job and felt as though they was making a difference.

## **Online End-of-Life Care Resources**

**Aging with Dignity**

<http://www.agingwithdignity.org/>

**American Academy of Hospice & Palliative Care Medicine (AAHPM)**

<http://aahpm.org/>

**American Cancer Society**

<http://www.cancer.org/index>

**American Geriatrics Society**

<http://www.americangeriatrics.org/>

**American Medical Association**

<http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/about-ethicsgroup/ethics-resource-center/end-of-life-care.page?>

**American Nurses Association**

<http://www.nursingworld.org/MainMenuCategories/EthicsStandards/End-of-Life>

**American Pain Foundation**

<http://www.painfoundation.org>

**American Pain Society**

<http://www.ampainsoc.org>

**Approaching Death: Improving Care at the End of Life**

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1070242/>

**Caregiver Network**

<http://caregivernetwork.org/>

**Caring Connections**

[www.caringinfo.org](http://www.caringinfo.org)

**Center to Advance Palliative Care (CAPC)**

<https://www.capc.org/>

**City of Hope**

<http://www.cityofhope.org/>

**Compassion & Choices**

<https://www.compassionandchoices.org/>

**Education on Palliative and End of Life Care project (EPEC)**

<http://www.epec.net/>

**End of Life Nursing Education Consortium (ELNEC)**

<http://www.aacn.nche.edu/elnec>

**Gerontological Society of America**

<http://www.geron.org/>

**Hospice Association of America**

<http://www.nahc.org/haa/>

**Hospice & Palliative Care Center**

<http://hospicecarecenter.org/>

**Hospice & Palliative Nurses Association**

<http://www.hpna.org/>

**Hospice Foundation of America**

<http://hospicefoundation.org/>

**Hospice Net**

<http://www.hospicenet.org/>

**Institute of Medicine End of Life Report**

<http://www.iom.edu/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>

**International Association for Hospice & Palliative Care**

<http://hospicecare.com/home/>

**National Caregivers Library**

<http://www.caregiverslibrary.org/caregivers-resources/grp-end-of-life-issues.aspx>

**National Consensus Project**

<http://www.nationalconsensusproject.org/>

**National Hospice & Palliative Care Organization (NHPCO)**

<http://www.nhpco.org/about-nhpco>

**National Institute on Aging**

<https://www.nia.nih.gov/>

**National Institute of Health**

<http://www.nih.gov>

**National Palliative Care Research Center (NPCRC)**

<http://www.npcrc.org/>

**Oncology Nursing Society**

<http://www.ons.org>

**Promoting Excellence in End of Life Care**

<http://www.promotingexcellence.org/>

**The Robert Wood Johnson Foundation (RWJF)**

<http://www.rwjf.org>

**Today's Caregiver**

<http://www.caregiver.com/index.htm>