1.1: 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.
- wing laws within the Ideal Gas Law

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
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 associated 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.

References

• Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsly, J. A. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA, 284*, 2476-2482.