

COPING WITH DEATH AND DYING

Camille B. Wortman

The death of a loved one is a ubiquitous human experience, one that is widely regarded as a serious threat to health and well-being. Consequently, it is important to understand how people cope with death and dying and whether some ways of coping are more adaptive than others. This voluminous research work can be divided into two broad categories: (a) how people cope with their own impending death or that of a loved one and (b) the grieving process that typically ensues after a loved one's death.

Among those studying how people cope with their own impending death or that of a loved one, variables such as the place of death, or the quality of care received by the dying, are of paramount importance. These variables play virtually no role in the study of the grieving process. Instead, grief researchers are more likely to examine such factors as how the person died, the mourner's attachment style, or the nature of the bereaved person's relationship with the deceased. Because of these differences in the focus of research, a review of studies in both of these areas is beyond the scope of this chapter. Consequently, I have chosen to examine how people cope with their own or a family member's imminent death. In particular, this chapter focuses on elderly individuals who are diagnosed with an incurable illness, their family members, and the health care professionals who attempt to meet their physical and psychological needs.

The vast majority of terminal illnesses occur among adults who are age 65 years or older.

According to U.S. Census data, the United States is likely to experience a marked increase in the number of elderly Americans and, consequently, in the total number of deaths. By 2050, the number of older Americans is expected to increase by 72% to nearly 90 million. Approximately three million baby boomers are expected to reach retirement age every year for the next 20 years, which will place enormous strain on an already-stressed health care system. Experts agree that this demographic shift is the most powerful force operating in the U.S. health care system today (Barr, 2014).

Most late-life deaths occur after a prolonged period of chronic illness such as coronary vascular disease, cancer, or Parkinson's disease (Carr, 2012). In many cases, the diseases that take the lives of older Americans are painful and debilitating, and they are often associated with cognitive impairments as well as physical decline. It is becoming increasingly apparent that dying is a process, not an event. In most cases, this process begins with the diagnosis of an incurable illness and ends with the patient's death. As a result of biomedical advances, the interval between diagnosis and death is becoming longer. Consequently, elderly people may spend many months living with dying (Golijani-Moghaddam, 2014).

When people receive a diagnosis of terminal illness, what can they and their family members expect from the health care system? Despite a growing number of research studies and calls for change,

This chapter represents a stimulating and rewarding collaboration between me and Nicole Barlé. Her passion for the subject, and her keen insights about the processes described, have made her a partner in the work.

<http://dx.doi.org/10.1037/14862-027>

APA Handbook of Clinical Psychology: Vol. 4. Psychopathology and Health, J. C. Norcross, G. R. VandenBos, and D. K. Freedheim (Editors-in-Chief)
Copyright © 2016 by the American Psychological Association. All rights reserved.

it is common for patients and family members to receive care that is substandard. In many cases, patients are not educated properly regarding their illness and treatment options, they are not treated with compassion, their wishes are not respected, communication between family and medical staff is sorely lacking, and evidence-based practices are not implemented (Gustafson, 2007).

In this chapter, I consider how people cope with their own impending death or that of a loved one and take a close look at end-of-life care as it is currently practiced in the United States. My goal is to describe the limitations of current care and explore ways in which it can be improved. In so doing, I also discuss what clinical psychologists can do to assist clients in coping with death and dying.

DEFINITION AND DESCRIPTION

Stage Models

Before examining end-of-life care and the coping challenges associated with it, it is important to examine theoretical models of how people cope with death and loss. Below, I introduce the theoretical approaches that have been most influential in the study of coping with death and dying. I focus primarily on stage models because for nearly 50 years, they have served as the guiding framework for understanding how people react to loss.

It is widely held that coping with death is a process that proceeds through a series of stages (Bowlby, 1980; Freud, 1917/1957). In 1969, Elizabeth Kübler-Ross published her book *On Death and Dying*, which described the stages people go through in coping with their own impending death. These stages are denial, anger, bargaining, depression, and finally acceptance. This model was embraced by professionals providing late-stage or end-of-life care. Within a few years, Kübler-Ross's model was being widely applied to individuals who were grieving the loss of a loved one. Indeed, Kübler-Ross wrote a book on this topic titled *On Grief and Grieving* (Kübler-Ross & Kessler, 2005).

Stage models have captured the imagination of health care providers and laypeople alike. For many years, Kübler-Ross's (1969) stage model has been integrated into the curriculum of countless

academic and professional schools throughout the country. It became a mainstay in training programs for doctors, nurses, psychologists, social workers, and members of the clergy. Kübler-Ross's stage model has also played a central role in how grief and loss are portrayed on influential websites, in the media, and in the self-help literature on death and dying.

Despite their widespread appeal, there is little empirical support for the existence of stages. Although some studies have purported to support stage models (Maciejewski et al., 2007), the weight of the evidence suggests that reactions to loss vary considerably from person to person and that few people pass through stages in the expected fashion (Pearlman et al., 2014). Available evidence has suggested that stage models are still taught in schools of medicine and nursing despite the absence of evidence to substantiate them. In one study of 23 commonly used textbooks for nursing students, 87% reported that there are stages of grief (Holman et al., 2010). The age of the books examined was unrelated to the endorsement of stage models, suggesting that new evidence is not being incorporated into the books.

Over time, some health care professionals have questioned the value of a stage-based approach. It has been noted that stage models can lead treatment providers to dismiss legitimate emotional reactions as "just a stage." Such an attribution may be made, for example, when a patient becomes angry because his request for more pain medication was ignored. In addition, stage models may lead health care providers to pathologize those who do not go through the stages. As a result of the widely held belief in Kübler-Ross's (1969) model, dying people who do not follow these stages may be labeled *deviant*, *neurotic*, or *pathological* dyers. It is common for doctors, nurses, and other health care professionals to become frustrated with patients who do not move from one stage to the next. They may also become resentful if the dying person does not reach a state of acceptance (Pattison, 1977). Such reactions are likely to interfere with the provision of compassionate care.

Despite practitioners' growing concerns about the value of stage models, no new overarching models of

copied with loss have gained prominence. This has led some investigators to conclude that stage models have exerted a virtual stranglehold on both research and treatment in this field. Why do health care providers hold onto stage models despite the lack of empirical support? Knowing what should come next may be helpful to them in navigating the difficult process of mourning. The stage models, though imperfect, may therefore provide needed comfort.

Beyond the Stage Models

Even proponents of the stage approach acknowledge that these models have a fundamental flaw: They fail to account for the striking individual differences that typically emerge after a loss. This issue is of paramount importance to practitioners, who benefit enormously from understanding why some people are devastated by a major loss while others emerge unscathed, or even strengthened. Knowledge of factors that influence vulnerability to loss can help practitioners identify those individuals most in need of care and to implement care that is more likely to be effective.

Consequently, there has been considerable interest in identifying specific factors that may influence how people confront their own death or that of a loved one. Research has focused on risk factors, such as inadequate financial resources or frail health, that are predictive of a poor outcome, and protective factors, such as the availability of social support, that facilitate effective coping.

A Good Death

Drawing from this work, I introduce the concept of a "good death." I identify the most commonly discussed characteristics of a good death, describe why it is so elusive, and discuss alternative forms of care that can improve the process of dying for patients and their family members. Exhibit 27.1 provides a list of qualities that have the potential to facilitate a good death. Some qualities address the importance of patients or caregivers having greater involvement in the process. Others focus on comfort and freedom from pain. Still others examine the setting in which care is delivered.

However, there is not one good death applicable to everyone. Some people value having information

Exhibit 27.1 Characteristics of a Good Death

- Receiving information about what can be expected
- Having some understanding about when death will occur
- Being at peace with one's impending death
- Freedom from pain
- Having loved ones nearby
- The opportunity to communicate with family members if and when desired
- Dying in a tranquil setting
- Terminally ill patients (and their family members) having control over decisions about end-of-life care
- Access to hospice care in the location of the patient's choice
- The opportunity to create advance directives to ensure wishes are understood and respected
- Dying with dignity without unnecessary prolonging of life
- Not feeling like a burden to loved ones
- The opportunity to affirm social bonds and repair damaged relationships
- Access to spiritual support if desired
- Having the opportunity to say goodbye to loved ones
- The opportunity to plan memorials and create legacies

about when death is likely to occur, whereas others have no interest in receiving such information, and may even go out of their way to avoid it. There are also striking differences in people's interest in interacting with others. As one person expressed it, "I lured nurses, techs, doctors, housekeepers and bringers-of-food into conversation" (Kastenbaum, 2004, p. 401). Another person found that he had no interest in talking about anything, even day-to-day matters going on in his family. "It leaves me cold, it doesn't engage me anymore. That's all over for me, meaningless" (Goldstein et al., 2006, p. 383).

INCIDENCE AND PREVALENCE

Where Americans Die

Several studies have surveyed Americans to determine their preferences regarding where they would like to die. Estimates across studies indicated that about 70% of Americans prefer to die at home. However, such deaths are relatively infrequent, occurring only about 20% of the time. Only a small percentage of respondents expressed a preference to die in a hospital or a nursing home. Yet, available data have indicated that approximately 60% of patients

die in the hospital, often after spending time in the intensive care unit (ICU). Approximately 20% of Americans die in a nursing home (Waldrop, 2014). It is difficult to determine how many patients die in hospice care. Hospice care usually takes place in the patient's home but may also be offered in residential facilities, hospice inpatient facilities, or nursing homes (National Hospice and Palliative Care Organization, 2012).

The conditions in most hospitals make it nearly impossible for a good death to be achieved. However, dying at home also poses considerable challenges for family members who are involved in the dying person's care. It appears that initially both patients and family members share an idealized fantasy of what dying at home entails (Henig, 2005). In this fantasy, the dying person is lying comfortably in bed, surrounded by loved ones who provide a supportive presence. However, family caregivers are typically overburdened and exhausted.

How Americans Die

Most studies that have examined how Americans die have focused on deaths that occur in hospital settings. Despite the prevalence of such deaths, evidence has suggested that in most cases, they are regarded by family members as agonizing. In one study (Prigerson et al., 2003), three quarters of the surviving family members indicated that they had witnessed their loved one in severe pain. For 62% of the respondents, this occurred daily. Family members reported that nearly 50% of the time, their loved one was unable to sleep, eat, or swallow. It is common for patients to have difficulty breathing and to consequently gasp for breath. In addition, 75% of patients were nonambulatory, 33% were incontinent, and 40% were cognitively impaired. Many were unable to reason or communicate and failed to recognize members of their own family. Vomiting and diarrhea were common. In other words, significant declines in quality of life had already occurred, raising questions about the merits of further intervention.

These data are put in further context when one considers the results of a study conducted by Ditto et al. (1996). Patients reported that they would rather die than experience significant pain or lose

their ability to think or reason. In other words, they viewed normal dying in a hospital as a fate worse than death.

Patients and family members expect that hospital physicians, nurses, and staff will provide state-of-the-art care and comfort. However, research has shown that hospitals, their ICUs and critical care units, are not caring places for the dying. In critical care units, it is common for physicians to prescribe life-sustaining treatments such as mechanical ventilation and resuscitation. Research has shown that ICU physicians initiate and continue such treatments even when they are likely to be futile. Nearly 50% of Medicare patients received invasive and expensive care just before death. In addition, nearly three quarters of ICUs admitted patients for whom there was no hope for recovery (Luce, 2010; Tilden et al., 2001). Doctors who are prescribing life-sustaining treatments may not communicate to patients or to family members that the patient's condition is terminal or may do so at the last minute. This communication failure often prohibits patients and family members from preparing for the death and sharing quality time (Beckstrand, Callister, & Kirchhoff, 2006). Perhaps for these reasons, aggressive treatments have been shown to decrease quality of life for patients and to impede the mourning process of family members (Wright et al., 2008).

Although there is a trend toward less aggressive treatment of terminally ill patients (Tilden et al., 2001), the practice still occurs with troubling frequency. Surprisingly, research has shown that most doctors would prefer to forgo aggressive treatments (Periyakoil, Neri, & Kraemer, 2015). Nonetheless, there is evidence that physicians often prescribe more aggressive care for their patients than they would choose for themselves (Connors et al., 1995). Moreover, 70% of medical residents reported that they go against their consciences when they use aggressive methods to treat dying patients while undertreating their discomfort and pain (Quill, 2000). Studies have shown that in some cases, invasive treatments are continued because the physician does not want to disappoint the family by "giving up" on the patient (Jox et al., 2012). Fear of legal consequences can also contribute to physicians' tendency to continue life-sustaining treatments.

If patients and family members have the opportunity to discuss their values and treatment preferences, aggressive treatment is much less likely to occur. In addition, dying patients are less likely to experience pain, less likely to die in the ICU, and more likely to be referred to hospice care (Periyakoil et al., 2015).

It is not uncommon for hospital patients with incurable illnesses to have multiple physicians and to receive conflicting reports about their condition. Consequently, hospitalized patients are often unable to identify the physician in charge of their case. Similarly, patients in skilled nursing facilities may not get to see their doctor more than once a month. In most hospitals, communication among physicians, dying patients, and family members about impending death is lacking (Beckstrand et al., 2006).

MAJOR INTERVENTIONS AND RESOURCES

Advance Directives and Do-Not-Resuscitate Orders

Margo is a 54-year-old woman who is very satisfied with her life. She has contracted a chest infection, which will kill her unless she is treated with antibiotics. This seems like a simple situation: She should take the antibiotics and live. However, Margo has dementia, and even though she is happy, she has an advance directive (AD) stating that should she become demented, any life-saving treatment should be refused.

An AD is a legal document in which patients identify specific actions to be taken during end-of-life care should they not be able to make decisions on their own (Shaw, 2012). Similarly, a living will is a legal document used to make known a person's wishes regarding life-prolonging treatments. Only one third to one half of all adults in the United States have an AD (Teno et al., 2007). A do-not-resuscitate (DNR) order is a legal document that expresses the wish of the patient to forgo cardiopulmonary resuscitation or advanced cardiac life support should their heart or breathing stop.

The likelihood of having an AD or living will is affected by many factors. One of the most important is age. Patients older than age 85 are more than twice as likely as those younger than age 65 to

have an AD (Jones, Moss, & Harris-Kojetin, 2011). Another factor, discussed in more detail later in this chapter, is race. Compared with White patients, African American patients in home health care and nursing homes were more than 50% less likely to have an AD (Jones et al., 2011).

Although these legal documents have the potential to improve the quality of death, there are obstacles to their implementation. Research has indicated that these documents are not standardized and are often vague and unclear. Many health care professionals are confused by what aspects of advance directives are legally binding or what these directives require them to do (Robinson et al., 2013). A study of 9,000 seriously ill patients determined that nearly half of all DNR orders were written just 2 days before death. Moreover, only half of the physicians were aware of their patient's DNR preferences (Quill, 2000). Even if the patient has completed an AD or DNR, physicians often ignore such directives if a family member insists that treatment continue.

In cases in which there is no AD, family members experience a marked escalation of stress and report feeling less prepared to deal with the situation (Wright et al., 2008). It is interesting that the main reason why older people do not have a living will is that they believe they can count on family members to carry out their wishes. However, most family members have virtually no understanding of their loved one's treatment preferences (Carr, Wortman, & Wolff, 2006).

Over the past decade, policymakers have shown a growing interest in ADs and DNR orders. It is now widely believed that such plans will protect the dying patient from aggressive and invasive care that is ultimately futile. According to research, there is a need for the standardization of advance care planning paperwork, as well as identification of the right time for health care professionals to initiate discussions about advance care planning with their patients.

Determining the optimal time to address these issues is particularly difficult in cases in which the prognosis is uncertain and in cases involving dementia (Robinson et al., 2013). Research has shown that witnessing the painful death of a loved

one can provide a powerful source of motivation to avoid experiencing such a death for oneself (Carr, 2012). By asking patients about their experiences with the deaths of loved ones, physicians can often identify the aspects of the end-of-life care that the patient wants to avoid and also determine the patient's wishes regarding the care he or she would like to receive. The situation faced by Margo in the above case example illuminates the difficulties inherent in the adoption of ADs and living wills. A critical question then arises regarding whose interests should be protected in Margo's case: the lucid Margo who drafted the AD, or the Margo with dementia who seems to have a life worth living?

Barriers to Conducting Effective End-of-Life Conversations

It is clear that overtreatment in ICU settings stems largely from communication problems among doctors, patients, and family members. In a recent study, young physicians involved in end-of-life care were asked to identify barriers to communicating effectively with their patients (Periyakoil et al., 2015). More than 99% of the doctors reported barriers in interactions with patients receiving end-of-life care, and more than 85% of doctors regarded end-of-life discussions with patients as very challenging, especially when dealing with patients whose ethnic backgrounds differed from their own.

One barrier concerns the limited English proficiency of many patients. Doctors expressed concern that medical terms such as *cardiopulmonary resuscitation* may not be fully understood by patients with limited language capabilities, leading to misunderstandings and miscommunication. A second barrier concerns patients' and families' religious beliefs about death and dying. For example, some patients believe that a person's death should be determined by the will of God. Such patients may oppose interventions even when they are likely to be successful.

Doctors' ignorance of patients' cultural beliefs constitutes a third barrier to effective communication. In some cultures, it is widely believed that even speaking about death will hasten the process. In other cultures, family members may insist that prognostic information be withheld from the patient because such information will cause the patient to

lose hope. Even commonly used words can mean different things to different people. One example concerns the English word *hospice*, which sounds like the Spanish word *hospicio*, which means "poor-house." Latino patients may think that the doctor is withholding expensive interventions and referring them to substandard care. In some cases, African American and Hispanic patients may believe that high-intensive interventions are being withheld because of racism.

Family Members

Family members are among the most important resources available to patients as they cope with their impending death. In most cases, however, the dying process is extremely stressful for family members, making it difficult for them to maintain a supportive presence.

As noted above, family members are likely to experience inordinate stress if they are required to make decisions about withdrawing or withholding life support from their loved one. In one study, 85% of deaths involved decisions to withhold or withdraw life-sustaining treatments (Tilden et al., 2001). Most family members report receiving little guidance from health care practitioners regarding how to make such decisions. As one family member commented about having to withhold care from his loved one, "I would not wish this on my own worst enemy" (Tilden et al., 2001, p. 111). Such family members are at moderate to major risk of developing posttraumatic stress disorder (Azoulay et al., 2005).

Of course, each setting in which death occurs is characterized by unique stressors for family members. Dying at home is typically associated with burdensome caregiver responsibilities. Research has shown that more than 50% of caregivers of patients with dementia report that they are on duty 24 hours a day. Similar to those whose family members are in the ICU, those who care for their loved ones at home report experiencing considerable uncertainty about their loved one's medical situation and how it should be handled. In addition, family caregivers are often required to manage complex medical regimens or implement different dietary changes that are difficult to understand (Carr et al., 2006). As a result, it is common for caregivers to become resentful or depressed.

Caregivers may also experience contradictory and confusing emotions about their role. David Shiflett (2014) served as a caregiver for his father, who was in the final stages of dementia. Because his father had no short-term memory, he would sometimes ask the same question five times in 1 minute. Shiflett noted that dealing with incidents like this produced mixed feelings: “sadness and exasperation, plus guilt for feeling exasperated, especially considering everything Dad and Mom had done for us.”

Family caregivers may also be struggling with practical issues such as how to fulfill their responsibilities at work and how to cover the costs of care. It is clear that in most cases, caregiving is associated with an enormous financial burden. Nearly one third of recently bereaved older adults indicate that they have lost all or most of their savings as a result of the costs of providing end-of-life care (Carr et al., 2006).

Another problem facing caregivers is that they typically receive conflicting input from multiple sources on their family member’s prognosis. There is consensus that caregivers are not adequately prepared by health care providers for their loved one’s death and all of its ramifications. Some health care providers assume that if the period of caregiving has been lengthy, the caregiver will be psychologically prepared for the loved one’s death. Unfortunately, this is not always the case (Hebert et al., 2009).

Many studies have documented the deleterious health consequences that are typically associated with caregiving (Buyck et al., 2011). Caregivers have been shown to have poorer immune function, greater vulnerability to physical illness, higher levels of stress, increased depression, and lower levels of subjective well-being (Carr et al., 2006).

The difficulties that physicians have in engaging in frank conversations are likely to emerge in interactions between patients and their family members as well. Family members may go along with physicians’ decisions regarding aggressive treatment because they do not want the patient to think they are giving up (Haley et al., 2003). Similarly, patients may endure more invasive treatment than they really want because they do not want to be seen as quitters. As death draws near, family members may be confused about what course of action

the patient prefers. This point was emphasized by Gustafson (2007), who struggled with what to say to his mother as her condition continued to deteriorate: “I kept asking myself: ‘What does Mom want?’ Does she want to die? Mom was awake. I could have asked her. But how? Do I say: ‘Mom, do you want to die?’ . . . And suppose she had said ‘Yes!’ Then what?” (p. 2).

Autonomy in a Good Death

A good death is frequently characterized by autonomy. It has been maintained that dying people should be able to make choices about how they want to die. There is consensus that a good death is one in which the dying person does so on his or her own terms. For example, Shneidman (2007) has maintained that for him, a good death means inflicting as little pain as possible on surviving family members. He recommended that dying individuals allow their death to reflect their better self: “Have your dying be . . . among the best things that you ever did. It is your last chance to get your neuroses under partial control” (p. 247). Byok (2004) has argued that a good death is far more likely if the dying person has the ability and the opportunity to express four thoughts to loved ones: (a) I love you, (b) thank you, (c) I forgive you, and (d) forgive me.

There is growing interest in the role that expressions of forgiveness might play in facilitating a good death. Studies have suggested that expressions of forgiveness can provide healing and closure for dying individuals and their family members (Exline et al., 2012). Those who saw expressions of forgiveness as important but did not have an opportunity to forgive or to ask for forgiveness were more likely to report symptoms of depression. If pronouncements of love, gratitude, and forgiveness are shown to result in more rewarding interactions and perceptions of a better death, these findings may be relatively easy to implement.

For the patient, the harsh realities of the dying process end once death occurs. This is not the case for the family. It is important to understand what factors make the grieving process more difficult because this will help to identify family members who would benefit from help and support. For example, family members whose loved ones

struggled with pain before their death showed a markedly higher number of intrusive thoughts. Painful deaths were also associated with elevated yearning and anxiety. If the survivor believed that the loved one received problematic medical care, she or he was more likely to experience anxiety and anger after the loved one's death. If the deceased contributed to his or her own death—for example, by smoking or excessive drinking—the bereavement process is more difficult.

Even in the ICU, with its limited opportunities for patient–family interaction, a treatment approach designed to increase communication between the dying person and his or her family had powerful effects (Lautrette et al., 2007). Family members were randomly assigned to customary care or to an intervention that included longer and more frequent opportunities for conversation with health care providers. This intervention for caregivers, summarized by the acronym VALUE, taught caregivers to value what family members said; to acknowledge the family member's emotions; to listen, to ask questions that would allow the caregiver to understand what the patient was going through, and to elicit information from the family members. Family members also received a brochure on bereavement that provided information about what to expect. Ninety days after the patient's death, family members in the treatment group showed lower scores on a standardized self-report measure of posttraumatic stress disorder symptoms. The treatment group also had significantly lower scores on measures of anxiety and depression. In other studies, treatments that facilitate communication between patients and families have resulted in significantly shorter stays in the ICU as well as lower costs (see, e.g., Ahrens, Yancey, & Kollef, 2003).

Avoidance

Both researchers and practitioners have reported that communications regarding end-of-life issues are powerfully influenced by avoidance. In our culture, feelings of avoidance of death are pervasive. Focusing on death, particularly one's own, often elicits feelings of uneasiness and dread. Most people find it uncomfortable to discuss such death-related topics as end-of-life care and desired funeral arrangements.

For some people, it is almost as though talking about these matters could make death more likely to occur.

As described earlier, avoidance can interfere with family communication about end-of-life care planning. Most adults with elderly parents have strong reservations against talking with their parents about end-of-life issues. As one person indicated, "I can't see myself asking dad whether he would rather be buried or cremated."

Avoidance may also underlie many people's reluctance to obtain an AD. In the future, it may be possible to establish guidelines in hospital settings mandating shared decision making through open communication, as well as documenting decisions that are made.

PALLIATIVE AND HOSPICE CARE

Over time, there has been increased recognition of the limitations of care received in hospital settings. Largely in reaction to these shortcomings, palliative and hospice care have emerged as appealing alternatives for people who are terminally ill. Both represent caring philosophies that emphasize the amelioration of pain and suffering associated with a serious, chronic, or terminal illness (Wright et al., 2008). Over the past 20 years, there has been a dramatic growth in these types of care (Case et al., 2013), which are designed to improve the quality of life of patients and their family members. Palliative and hospice care address patient and family concerns regarding emotional, physical, and spiritual well-being. Their goal is to provide coordinated, comprehensive medical care and relief of suffering and to ensure that patients are treated with dignity and respect. They also facilitate communication among patients, health care providers, and family members. In addition, these forms of care offer support to family members before and after the death of their loved ones (e.g., Costello, 2006; Pyenson et al., 2004; Strada & Breitbart, 2009).

Differences in Focus

Although they share a basic treatment philosophy, there are important differences between palliative and hospice care. Palliative care may be received

in addition to curative treatment. For example, a cancer patient may undergo chemotherapy while seeing a specialist for pain management and regularly meeting with a therapist for emotional support. In most cases, those in hospice care have accepted their terminal diagnosis, have 6 months or less to live, and have opted not to receive life-prolonging treatments. In contrast, palliative care is designed for patients with varying types of disease, including those with curable illnesses. Hospice care can be regarded as the palliation of the terminally ill, providing support to patients who are very near death (Connor et al., 2007). Both hospice and palliative care use a multidisciplinary approach, using the services of physicians, nurses, social workers, psychologists, chaplains, and other health service providers (Quest et al., 2012). In addition, hospice care often also includes such comforting services as bedside companionship and relief for exhausted caregivers.

Nearly 75% of hospice patients receive treatment in their homes (Morrison et al., 2005). In contrast, palliative care is practiced primarily in hospital settings (Morrison et al., 2005). The number of hospitals and home care services offering such care has increased exponentially over the past decade. This is particularly the case in larger hospitals, such as those affiliated with universities and the Department of Veterans Affairs (Morrison et al., 2005).

Outcomes of Palliative and Hospice Care

Research has provided compelling evidence of the effectiveness of both palliative and hospice care across a broad range of outcomes. Many studies have reported substantial reductions in costs for palliative care compared with conventional care (Connor et al., 2007; Meier, 2004). As a result of empathic discussions with health care providers, patients may decide to forgo aggressive end-of-life care, which can lead to dramatic cost reductions. These cost reductions are also present for hospice care compared with conventional care (Connor et al., 2007; Meier, 2004). In these studies, reduced costs are not accounted for by shorter time to death. In fact, in some studies of hospice patients, lives were prolonged for as long as a month (Connor et al., 2007; Pyenson et al., 2004). At this time, it is not clear how or why hospice care prolongs life, but

it is reasonable to assume that the comfort of being in familiar surroundings, the reduction of stress, the amelioration of pain, the presence of family, and the acceptance of one's final wishes are important factors.

Palliative care can provide a higher quality of life for patients—often preventing the difficult and stressful cycle of being moved from their homes to nursing homes to hospital emergency departments and back again. In hospitals, patients often receive only emergency care, such as resuscitation, stabilization, and temporary pain relief (Quest et al., 2012). As noted earlier, patients' care goals, such as a DNR order, and decision-making needs, such as being properly informed of all of their available options, are frequently not addressed in that setting (Quest et al., 2012).

Many studies have reported higher rates of satisfaction with hospice care among both patients and their families. Families of hospice patients have consistently indicated that they were more pleased with the medical care and physician communication in the hospice environment than were those who were cared for in nursing homes, in hospitals, or at home with nursing services (Teno et al., 2004). Families of patients who used hospice care were also less likely to say that their loved one suffered unnecessary pain. Bereaved older Americans reported fewer anxiety symptoms before the loss and fewer depression symptoms during bereavement when their loved one was under hospice care (Miller et al., 2000). Research has further indicated that those in hospice care experience fewer hospitalizations and less invasive and less aggressive treatments, such as intravenous fluids and tube feedings (Miller et al., 2000).

Compared with conventional care, hospice care may reduce the increased mortality risk associated with bereavement (Christakis & Iwashyna, 2003). Eighteen months after their husbands' death, there were significantly fewer deaths among wives whose husbands had received hospice care than among those who received other types of care. Mortality was also lower for husbands whose wives received hospice care, but the effect fell short of statistical significance. This is perhaps because in most cases, hospice provides bereavement support for as much as 18 months after the death of a loved one.

Underutilization of Palliative and Hospice Care

Studies of end-of-life care have shown that some types of care tend to be underused by segments of the American population. African American patients, for example, use hospice services at a rate that is statistically lower than that of White Americans, even after controlling for gender, marital status, education, medical history, existence of a living will, religiosity, income, and access to health care (Cohen, 2008). Regardless of prognosis, African American patients are more likely than White patients to request aggressive treatments, resulting in higher rates of hospitalization, cardio-pulmonary resuscitation, and in-hospital deaths (Johnson, Kuchibhatla, & Tulskey, 2011). Evidence has suggested that African American patients are more likely than White patients to resist hospice referral (Ache et al., 2011).

African American patients also appear to have less exposure to information regarding hospice services than White patients (Johnson et al., 2011). Patients who indicated that they had fewer financial resources expressed the greatest need for the types of services provided by hospice (Fishman et al., 2009). African Americans are less likely than Whites to have a usual source of health care, and visit a primary care physician fewer times in the last year of life (Johnson et al., 2011). Patients without access to regular primary care may be referred to specialists and alternative care (palliative care and hospice) at later stages in the course of an illness than White patients. Receiving diagnosis at a later stage in the course of a disease limits opportunities for discussions regarding the prognosis of the illness, treatment, advanced care planning, and hospice care in nonacute settings (Fishman et al., 2009). The absence of regular care may contribute to African American patients' lack of knowledge regarding the palliative care and end-of-life services available to them.

FUTURE DIRECTIONS

Roles of Clinical Psychologists

Research reviewed in this article points to one overarching theme: Addressing patients' psychological

needs is as important, if not more important, than managing their physical care. It is clear that clinical psychologists have much to contribute to end-of-life care. Historically, psychologists have had a limited role in providing such care, and this is particularly true in palliative care settings. One researcher emphasized that a small number of psychologists have been the unsung workers in hospice care, going virtually unnoticed amid a collection of counselors, social workers, chaplains, nurses, and volunteers (Hartman-Stein, 2001).

End-of-life issues are becoming increasingly salient for clinical psychologists because they excel at the treatment of many symptoms that are likely to emerge during end-of-life care, including those associated with anxiety and depression (Haley et al., 2003). Clinicians have much to offer clients in need of pain management. Furthermore, they typically have a good understanding of family dynamics and can facilitate constructive communication between patients and family members.

Because of their skills and knowledge base, psychologists have the potential to make important contributions to virtually every phase of end-of-life care. Phases identified by Haley et al. (2003) include (a) the time at which the terminal illness is diagnosed and treatments are initiated, (b) the time at which the treatments are no longer effective and decisions must be made about aggressive versus palliative care, and (c) the time at which the patient's death is imminent.

After terminal illness has been diagnosed, psychologists can help patients and family members to understand the diagnosis and its ramifications. They can treat commonly occurring symptoms of anxiety and depression. Clinical psychologists can help newly diagnosed patients clarify their treatment preferences—documenting them in written form and communicating them to their physicians. Research has consistently shown that attending to these issues early in the process is associated with more favorable outcomes. The presence of these documents can alleviate the profound stress experienced by family members who are required to make medical decisions but do not know the patient's preferences. If the patient does not have these orders on file, the clinician can help in drafting the

documents, ideally with input from family members. Clinicians can also help to ensure that the patient's preferences are known to both health care providers and family members.

Once the focus of care shifts from curative to palliative treatment, a number of new issues emerge. In addition to dealing with their own impending death, most patients are deeply concerned about how their death will affect loved ones. Clinicians can assist patients and family members in exploring their apprehensions. Clinicians can also help by addressing existential or spiritual concerns that often emerge at this time. For example, patients may be experiencing deep regrets about previous life decisions and may benefit from the opportunity to voice these concerns.

The dying process often engenders strong feelings of helplessness and lack of control. Interventions designed to address these feelings can prove invaluable to patients and their family members. These interventions may include relaxation and breathing techniques, meditation, guided imagery, or goal setting (Haley et al., 2003). As death draws near, clinicians also have the opportunity to facilitate constructive interactions between patients and family members. For example, they can encourage all parties to express feelings of love and to ask for forgiveness before it is too late.

Planned Suicide

A new trend in alternative end-of-life care that will become increasingly important in the future is planned suicide. Planned and open suicides may represent a form of ultimate self-determination for those who are terminally ill. Diagnosed with Alzheimer's disease in 2010, noted psychologist Sandra Bem chose just such an option for herself. In consultation with her husband and family, Bem publicly decided that if and when her condition prevented her from having a meaningful quality of life, she would take her own life at the last possible moment she could still do so without help ("Sandra Bem," 2014; Spiegel, 2014). It was Bem's hope that by making her plan a collective one, she would alleviate as much pain as possible for her loved ones. Bem's decision fostered open discussion, support, and the ability for loved ones to gather with Bem at

her home just before her death to honor her (Spiegel, 2014).

More recently, the tragic end-of-life story of Britanny Maynard raised awareness of the death-with-dignity movement in the United States. Maynard, a 29-year-old newlywed with terminal brain cancer, elected to move from California to Oregon so that she could obtain a prescription from a physician to end her life when she was ready to do so. Maynard went public with the difficulties of her ordeal: uprooting her family, locating and purchasing a new home, finding new physicians, establishing Oregon residency, obtaining a new driver's license, changing her voter registration, arranging care for her pets in California, and the necessity for her husband to take a leave of absence from his place of employment (Maynard, 2014). Maynard ended her life peacefully on November 1, 2014, surrounded by her family.

Physician-assisted suicide, legal in five U.S. states (Oregon, Washington, Vermont, Montana, and New Mexico) as of January 2015, allows patients to obtain lethal prescriptions from their physicians to help them commit suicide. To obtain such a prescription in the state of Oregon, for example, the Death With Dignity Act (DWDA) requires that a patient be an adult (age 18 years or older); a resident of Oregon; able to make and communicate health care decisions; and diagnosed with a terminal illness that will lead to death within 6 months. For patients meeting these requirements to request lethal medication from a licensed Oregon physician, the following steps must be fulfilled: The patient must make two oral requests to his or her physician, separated by at least 15 days; the patient must provide a written request to his or her physician, signed in the presence of two witnesses; the prescribing physician and consulting physician must confirm the diagnosis and prognosis; and the prescribing physician and consulting physician must determine whether the patient is capable of making health care decisions. If either physician believes the patient's judgment is impaired by a mental disorder, the patient must be referred for a psychological examination; the prescribing physician must inform the patient of feasible alternatives to physician-assisted suicide, including comfort

care, hospice care, and pain control; and the prescribing physician must request that the patient notify his or her next of kin of the prescription request. To be compliant with this law, physicians must report to the Department of Human Services all prescriptions for lethal medications. Pharmacists must also be informed of the medication's intended use ("Death With Dignity Act Requirements," 2011). Moreover, it is specified that action taken in accordance with the DWDA is not defined as suicide, but that the cause of death listed on death certificates be the terminal illness from which the patient suffers. This provision protects the status of health or life insurance policies for those who choose DWDA ("Death With Dignity Act Requirements," 2011).

The DWDA has been fraught with controversy since its inception in 1997. Proponents claim that it simply provides mentally competent terminally ill patients a choice in the way they die. A recent study of 95 families of Oregonian patients who requested physician aid in dying showed that, compared with a control group, family members of patients who were aided in dying felt, on average, more accepting and ready for their loved one's death (Ganzini et al., 2009). Those opposing the act originally felt that the law might be used irresponsibly and that citizens of other states would flock to Oregon to die. However, lethal medication prescriptions were written for 122 people in 2013 under the provision of the DWDA, compared with 116 in 2012, representing approximately 21.9 DWDA deaths per 10,000 total deaths (Oregon Public Health Department, 2014).

Gallup polls consistently show that about 70% of Americans support doctors in providing "some painless means if the patient and his or her family request it" (Sanburn, 2014). Yet, despite its popular support, death with dignity fails at the government level in a majority of states. It now appears that through death, Brittany Maynard has breathed new life into the death-with-dignity movement. As of February 2015, death-with-dignity legislation is pending in several additional U.S. states. This topic continues to be hotly debated in the United States, but will become of increased research and practice emphasis in the next decade.

Toward a Good Death

A good death is an ideal toward which clinical psychologists, other health care providers, dying patients, and family members should strive (Exhibit 27.1). Policymakers and health professionals have developed guidelines that are designed to facilitate a good death. Yet these efforts to improve the process of dying have been only partially successful. Given the dramatic increase in the number of deaths anticipated in the United States, finding ways to promote good deaths should be considered a moral and ethical imperative.

References

- Ache, K. A., Shannon, R. P., Heckman, M. G., Diehl, N. N., & Willis, F. B. (2011). A preliminary study comparing attitudes toward hospice referral between African American and White American primary care physicians. *Journal of Palliative Medicine, 14*, 542–547. <http://dx.doi.org/10.1089/jpm.2010.0426>
- Ahrens, T., Yancey, V., & Kollef, M. (2003). Improving family communications at the end of life: Implications for length of stay in the intensive care unit and resource use. *American Journal of Critical Care, 12*, 317–323.
- Azoulay, E., Pochard, F., Kentish-Barnes, N., Chevret, S., Aboab, J., Adrie, C., . . . Schlemmer, B.; FAMIREA Study Group. (2005). Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *American Journal of Respiratory and Critical Care Medicine, 171*, 987–994. <http://dx.doi.org/10.1164/rccm.200409-1295OC>
- Barr, P. (2014, January 14). *The boomer challenge: A generation that has dominated American life for a half-century will have an enormous impact on health care as it ages*. Retrieved from http://www.hhnmag.com/display/HHN-news-article.dhtml?dcrPath=/templatedata/HF_Common/NewsArticle/data/HHN/Magazine/2014/Jan/cover-story-baby-boomers
- Beckstrand, R. L., Callister, L. C., & Kirchhoff, K. T. (2006). Providing a "good death": Critical care nurses' suggestions for improving end-of-life care. *American Journal of Critical Care, 15*, 38–45.
- Bowlby, J. (1980). *Attachment and loss: Vol. 3. Loss: Sadness and depression. (Attachment and loss, Vol. 3)*. New York, NY: Basic Books.
- Buyck, J. F., Bonnaud, S., Boumendil, A., Andrieu, S., Bonenfant, S., Goldberg, M., . . . Ankri, J. (2011). Informal caregiving and self-reported mental and physical health: Results from the Gazel Cohort Study. *American Journal of Public Health, 101*, 1971–1979. <http://dx.doi.org/10.2105/AJPH.2010.300044>

- Byok, I. (2004). *The four things that matter most: A book about living*. New York, NY: Free Press.
- Carr, D. (2012). "I don't want to die like that . . .": The impact of significant others' death quality on advance care planning. *Gerontologist*, *52*, 770–781. <http://dx.doi.org/10.1093/geront/gns051>
- Carr, D., Wortman, C. B., & Wolff, K. (2006). How older Americans die today: Implications for surviving spouses. In D. Carr, R. Nesse, & C. B. Wortman (Eds.), *Spousal bereavement in late life* (pp. 49–80). New York, NY: Springer.
- Case, A. A., Orrange, S. M., & Weissman, D. E. (2013). Palliative medicine physician education in the United States: A historical review. *Journal of Palliative Medicine*, *16*, 230–236. <http://dx.doi.org/10.1089/jpm.2012.0436>
- Christakis, N. A., & Iwashyna, T. J. (2003). The health impact of health care on families: A matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. *Social Science and Medicine*, *57*, 465–475. [http://dx.doi.org/10.1016/S0277-9536\(02\)00370-2](http://dx.doi.org/10.1016/S0277-9536(02)00370-2)
- Cohen, L. L. (2008). Racial/ethnic disparities in hospice care: A systematic review. *Journal of Palliative Medicine*, *11*, 763–768. <http://dx.doi.org/10.1089/jpm.2007.0216>
- Connor, S. R., Pyenson, B., Fitch, K., Spence, C., & Iwasaki, K. (2007). Comparing hospice and nonhospice patient survival among patients who die within a three-year window. *Journal of Pain and Symptom Management*, *33*, 238–246. <http://dx.doi.org/10.1016/j.jpainsymman.2006.10.010>
- Connors, A. F., Jr., Dawson, N. V., Desbiens, N. A., Fulkerson, W. J., Goldman, L., Knaus, W. A., . . . Ransohoff, D.; SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA*, *274*, 1591–1598. <http://dx.doi.org/10.1001/jama.1995.03530200027032>
- Costello, J. (2006). Dying well: Nurses' experiences of "good and bad" deaths in hospital. *Journal of Advanced Nursing*, *54*, 594–601. <http://dx.doi.org/10.1111/j.1365-2648.2006.03867.x>
- Death with dignity act requirements*. (2011). Retrieved from <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/requirements.pdf>
- Ditto, P. H., Druley, J. A., Moore, K. A., Danks, J. H., & Smucker, W. D. (1996). Fates worse than death: The role of valued life activities in health-state evaluations. *Health Psychology*, *15*, 332–343. <http://dx.doi.org/10.1037/0278-6133.15.5.332>
- Exline, J. J., Prince-Paul, M., Root, B. L., Peereboom, K. S., & Worthington, E. L., Jr. (2012). Forgiveness, depressive symptoms, and communication at the end of life: A study with family members of hospice patients. *Journal of Palliative Medicine*, *15*, 1113–1119. <http://dx.doi.org/10.1089/jpm.2012.0138>
- Fishman, J., O'Dwyer, P., Lu, H. L., Henderson, H. R., Asch, D. A., & Casarett, D. J. (2009). Race, treatment preferences, and hospice enrollment: Eligibility criteria may exclude patients with the greatest needs for care. *Cancer*, *115*, 689–697. <http://dx.doi.org/10.1002/cncr.24046>
- Freud, S. (1957). Mourning and melancholia. In J. Strachey (Ed.), *The standard edition of the complete works of Sigmund Freud* (Vol. 14, pp. 152–170). London, England: Hogarth Press. (Original work published 1917)
- Ganzini, L., Goy, E. R., Dobscha, S. K., & Prigerson, H. (2009). Mental health outcomes of family members of Oregonians who request physician aid in dying. *Journal of Pain and Symptom Management*, *38*, 807–815. <http://dx.doi.org/10.1016/j.jpainsymman.2009.04.026>
- Goldsteen, M., Houtepen, R., Proot, I. M., Abu-Saad, H. H., Spreeuwenberg, C., & Widdershoven, G. (2006). What is a good death? Terminally ill patients dealing with normative expectations around death and dying. *Patient Education and Counseling*, *64*, 378–386. <http://dx.doi.org/10.1016/j.pec.2006.04.008>
- Golijani-Moghaddam, N. (2014). Practitioner psychologists in palliative care: Past, present, and future directions. *Counselling Psychology Review*, *29*, 29–40.
- Gustafson, D. H. (2007). A good death. *Journal of Medical Internet Research*, *9*, e6. <http://dx.doi.org/10.2196/jmir.9.1.e6>
- Haley, W. E., Larson, D. G., Kasl-Godley, J., Neimeyer, R. A., & Kwilosz, D. M. (2003). Roles for psychologists in end-of-life care: Emerging models of practice. *Professional Psychology: Research and Practice*, *34*, 626–633. <http://dx.doi.org/10.1037/0735-7028.34.6.626>
- Hartman-Stein, P. E. (2001). Psychologists trying to overcome barriers to work with hospice patients. *National Psychologist*, *10*, 12–13.
- Hebert, R. S., Schulz, R., Copeland, V. C., & Arnold, R. M. (2009). Preparing family caregivers for death and bereavement: Insights from caregivers of terminally ill patients. *Journal of Pain and Symptom Management*, *37*, 3–12. <http://dx.doi.org/10.1016/j.jpainsymman.2007.12.010>
- Henig, R. M. (2005, August 7). Will we ever arrive at the good death? *New York Times*. Retrieved from <http://www.nytimes.com/2005/08/07/magazine/will-we-ever-arrive-at-the-good-death.html>
- Holman, E. A., Perisho, J., Edwards, A., & Mlakar, N. (2010). The myths of coping with loss in

- undergraduate psychiatric nursing books. *Research in Nursing and Health*, 33, 486–499. <http://dx.doi.org/10.1002/nur.20407>
- Johnson, K. S., Kuchibhatla, M., & Tulsy, J. A. (2011). Racial differences in location before hospice enrollment and association with hospice length of stay. *Journal of the American Geriatrics Society*, 59, 732–737. <http://dx.doi.org/10.1111/j.1532-5415.2011.03326.x>
- Jones, A. L., Moss, A. J., & Harris-Kojetin, L. D. (2011). *Use of advance directives in long-term care populations* (NCHS Data Brief No.54). Hyattsville, MD: National Center for Health Statistics.
- Jox, R. J., Schaider, A., Marckmann, G., & Borasio, G. D. (2012). Medical futility at the end of life: The perspectives of intensive care and palliative care clinicians. *Journal of Medical Ethics*, 38, 540–545. <http://dx.doi.org/10.1136/medethics-2011-100479>
- Kastenbaum, R. (2004). *On our way: The final passage through life and death*. Berkeley: University of California Press.
- Kübler-Ross, E. (1969). *On death and dying*. New York, NY: Springer.
- Kübler-Ross, E., & Kessler, D. (2005). *On grief and grieving: Find the meaning of grief through the five stages of loss*. New York, NY: Simon & Schuster.
- Lautrette, A., Darmon, M., Megarbane, B., Joly, L. M., Chevret, S., Adrie, C., . . . Azoulay, E. (2007). A communication strategy and brochure for relatives of patients dying in the ICU. *New England Journal of Medicine*, 356, 469–478. <http://dx.doi.org/10.1056/NEJMoa063446>
- Luce, J. M. (2010). End-of-life decision making in the intensive care unit. *American Journal of Respiratory and Critical Care Medicine*, 182, 6–11. <http://dx.doi.org/10.1164/rccm.201001-0071CI>
- Maciejewski, P. K., Zhang, B., Block, S. D., & Prigerson, H. G. (2007). An empirical examination of the stage theory of grief. *JAMA*, 297, 716–723. <http://dx.doi.org/10.1001/jama.297.7.716>
- Maynard, B. (2014). My right to death with dignity at 29. Retrieved from <http://www.cnn.com/2014/10/07/opinion/maynard-assisted-suicide-cancer-dignity/index.html>
- Meier, D. E. (2004). Variability in end of life care. *BMJ*, 328, E296–E297. <http://dx.doi.org/10.1136/bmj.328.7449.E296>
- Miller, S., Mor, V., Gage, B., & Coppola, K. (2000). Hospice and its role in improving end of life care. In M. P. Lawton (Ed.), *Annual review of gerontology and geriatrics* (Vol. 20, pp. 193–223). New York, NY: Springer.
- Morrison, R. S., Maroney-Galin, C., Kralovec, P. D., & Meier, D. E. (2005). The growth of palliative care programs in United States hospitals. *Journal of Palliative Medicine*, 8, 1127–1134. <http://dx.doi.org/10.1089/jpm.2005.8.1127>
- National Hospice and Palliative Care Organization. (2012). *NHPCO facts and figures: Hospice care in America*. Alexandria, VA: Author.
- Oregon Public Health Department. (2014). *Oregon's Death With Dignity Act—2013* (Death With Dignity Act Annual Report). Retrieved from <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf>
- Pattison, E. M. (1977). *The experience of dying*. Englewood Cliffs, NJ: Prentice-Hall.
- Pearlman, L. A., Wortman, C. B., Feuer, C., Farber, C., & Rando, T. (2014). *Traumatic bereavement: A practitioner's guide*. New York, NY: Guilford Press.
- Periyakoil, V. S., Neri, E., & Kraemer, H. (2015). No easy talk: A mixed methods study of doctor reported barriers to conducting effective end-of-life conversations with diverse patients. *PLoS ONE*, 10, e0122321. <http://dx.doi.org/10.1371/journal.pone.0122321>
- Prigerson, H. G., Cherlin, E., Chen, J. H., Kasl, S. V., Hurzeler, R., & Bradley, E. H. (2003). The Stressful Caregiving Adult Reactions to Experiences of Dying (SCARED) Scale: A measure for assessing caregiver exposure to distress in terminal care. *American Journal of Geriatric Psychiatry*, 11, 309–319. <http://dx.doi.org/10.1097/00019442-200305000-00008>
- Pyenson, B., Connor, S., Fitch, K., & Kinzbrunner, B. (2004). Medicare cost in matched hospice and non-hospice cohorts. *Journal of Pain and Symptom Management*, 28, 200–210. <http://dx.doi.org/10.1016/j.jpainsymman.2004.05.003>
- Quest, T. E., Chan, G. K., Derse, A., Stone, S., Todd, K. H., & Zalenski, R. (2012). Palliative care in emergency medicine: Past, present, and future. *Journal of Palliative Medicine*, 15, 1076–1081. <http://dx.doi.org/10.1089/jpm.2012.9553>
- Quill, T. E. (2000). Perspectives on care at the close of life. Initiating end-of-life discussions with seriously ill patients: Addressing the “elephant in the room.” *JAMA*, 284, 2502–2507. <http://dx.doi.org/10.1001/jama.284.19.2502>
- Robinson, L., Dickinson, C., Bamford, C., Clark, A., Hughes, J., & Exley, C. (2013). A qualitative study: Professionals' experiences of advance care planning in dementia and palliative care, “a good idea in theory but. . .” *Palliative Medicine*, 27, 401–408. <http://dx.doi.org/10.1177/0269216312465651>
- Sanburn, J. (2014). Brittany Maynard could revive the stalled “death with dignity” movement. *Time*. Retrieved from <http://time.com/3551089/brittany-maynard-death-with-dignity>

- Sandra Bem. (2014, May 25). *New York Times*. Retrieved from <http://www.legacy.com/obituaries/nytimes/obituary.aspx?pid=171123544&module=Search&mabReward=relbias%3Ar>
- Shaw, D. (2012). A direct advance on advance directives. *Bioethics*, 26, 267–274. <http://dx.doi.org/10.1111/j.1467-8519.2010.01853.x>
- Shiflett, D. (2014, June 27). Life lessons from dad: Caring for an elderly parent. *Wall Street Journal*. Retrieved from <http://online.wsj.com/articles/life-lessons-from-dad-caring-for-an-elderly-parent-1403886423>
- Shneidman, E. (2007). Criteria for a good death. *Suicide and Life-Threatening Behavior*, 37, 245–247. <http://dx.doi.org/10.1521/suli.2007.37.3.245>
- Spiegel, A. (2014, June 23). *How a woman's plan to kill herself helped her family grieve*. Retrieved from <http://www.npr.org/blogs/health/2014/06/23/323330486/how-a-womans-plan-to-kill-herself-helped-her-family-grieve>
- Strada, E. A., & Breitbart, W. (2009). Addressing the psychological and psychiatric domain of palliative care. *Primary Psychiatry*, 16, 23–24.
- Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R., & Mor, V. (2004). Family perspectives on end-of-life care at the last place of care. *JAMA*, 291, 88–93. <http://dx.doi.org/10.1001/jama.291.1.88>
- Teno, J. M., Gruneir, A., Schwartz, Z., Nanda, A., & Wetle, T. (2007). Association between advance directives and quality of end-of-life care: A national study. *Journal of the American Geriatrics Society*, 55, 189–194. <http://dx.doi.org/10.1111/j.1532-5415.2007.01045.x>
- Tilden, V. P., Tolle, S. W., Nelson, C. A., & Fields, J. (2001). Family decision-making to withdraw life-sustaining treatments from hospitalized patients. *Nursing Research*, 50, 105–115. <http://dx.doi.org/10.1097/00006199-200103000-00006>
- Waldrop, D. (2014). Exploring hospice decisions: The road from the Institute on Aging and Social Work to an ARRA Challenge Grant. *Educational Gerontology*, 40, 248–257. <http://dx.doi.org/10.1080/03601277.2014.852931>
- Wright, A. A., Zhang, B., Ray, A., Mack, J. W., Trice, E., Balboni, T., . . . Prigerson, H. G. (2008). Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*, 300, 1665–1673. <http://dx.doi.org/10.1001/jama.300.14.1665>