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Chapter 14: Hospice and End-of-Life Care
Sally Pelon, Brandon Youker, and M. Paola León

Abstract

This chapter explores end-of-life issues and concerns as well as the hospice movement's role in assisting terminally ill individuals. Specific social work assessment and interventions tools are offered considered as well as controversial issues in end-of-life care.

Case Study 14.1

Frances Jones is a 65 year old African American woman recently admitted to hospice care with metastatic breast cancer. She was diagnosed just six months ago. Mrs. Jones was initially told that treatment was not an option as her cancer had spread to her liver and bone. However, Mrs. Jones pleaded with her oncologist to 'try anything' and the oncologist reluctantly agreed to a few rounds of chemotherapy. This treatment had no impact on her disease and also made Mrs. Jones nauseous and very tired. She discontinued treatment at her oncologist's urging. Mrs. Jones was wary of signing on to hospice care, but unenthusiastically agreed when her son Marcus insisted she needed Hospice's help.

Mrs. Jones currently resides in her own home. Her 30 year old son, Marcus recently moved in with his mother due to her declining health and increasing care needs. He works long hours as an engineer for an automotive company and is less available to his mother than he would like. Marcus completes all household chores including cooking, cleaning, and grocery shopping, but struggles to keep up with these responsibilities as well as with his mother's increasing care needs. Marcus has been very close to his mother throughout his life.

Mrs. Jones' daughter Gwen, age 36, resides out of state with her husband and two school age children. Her demanding job and family responsibilities have prevented her from visiting her mother as often as she would like. Marcus is upset that Gwen is not more helpful and reports that he believes Gwen fails to understand the seriousness of their mother's illness or the difficulty he is having juggling care for their mother with his work responsibilities. Marcus is also concerned that his mother requires more assistance than he is able to provide but he is also certain that she will be unwilling to move to a facility that is able to provide increased care and support to her.

Marcus describes his mother as stubborn, independent, and strong. She raised her children on her own when her husband and the children's father was killed in a car accident 25 years ago. Mrs. Jones worked two jobs in order to support herself and her children and insisted that both Gwen and Marcus attend college to 'make something of themselves.'

Case Study 14.2

John Jordan is an 85-year-old Caucasian man with end-stage Alzheimer's dementia, who was transferred to the hospital from his extended-care facility with suspected pneumonia. The pneumonia is likely due to aspiration, as Mr. Jordan has been noted to have difficulty swallowing for the past couple of months. In the hospital, his clinical presentation and chest X-ray were consistent with aspiration pneumonia. His doctor started Mr. Jordan on appropriate antibiotics to treat the pneumonia, and his condition improved over the course of several days. The attending physician then ordered a swallow study and a nutrition consultation, which confirmed that Mr. Jordan has severe dysphagia with aspiration. Consequently, the physician offered to place a feeding tube for Mr. Jordan so that he can continue to receive necessary calories and nutrients without the risk of aspiration.

Mr. Jordan's family includes his wife, Mabel, age 83, and his three adult children, David, age 62, Bonnie, age 60, and Jack, age 57. Mrs. Jordan has significant health problems and has been minimally involved in decision making regarding Mr. Jordan's care due to her own health concerns. Mr. Jordan's oldest son David is his appointed Medical Power of Attorney. He has been a fine advocate and decision-maker for his father's care and treatment and has routinely talked over care and treatment decisions with his siblings and sought their agreement prior to making any major care and treatment decisions for their father. The decision regarding the feeding tube placement has been a difficult and divisive for the family. David believes that to place a feeding tube will needlessly prolong his father's suffering and impending death while Bonnie and Jack believe that without the feeding tube, Mr. Jordan will 'starve to death.'

History of the Hospice Movement

The word 'hospice' is derived from the Latin words *hospitium*, which means hospitality, and *hospis* meaning guest or stranger (Connor, 2009). The notion of providing hospitality for the sick and disabled dates back to 17th century Europe, where monasteries often served as places of refuge for travelers and those in need of care (Noe, Smith, & Younis, 2012). Hospice as a reference to specialized care for the dying was first used by [Dr. Cicely Saunders](#), who began working extensively with the terminally ill in England in the late 1940s. In 1967, Saunders established St. Christopher's Hospice in London, the first modern hospice and the catalyst for the hospice movement (Connor, 2007). From the beginning, Saunders challenged the traditional medical model of care in which those with advanced illness were treated as having physical deficits to be aggressively managed or 'fixed' (DiTullio & MacDonald, 1999), and advocated instead for the emotional, spiritual, and physical comfort of the dying through a holistic and interprofessional approach to care (Noe et al., 2012) and the recognition of death as the natural and final life stage (DiTullio & MacDonald, 1999).

Saunders introduced the concept of hospice in the United States in 1963, during a speech to medical students, nurses, social workers, and chaplains at Yale University. However, it was not until 1974 that the first hospice was established in the United States in Branford, Connecticut by Florence Wald, Dean of the School of Nursing at Yale University, along with two pediatricians and a chaplain ([National Hospice and Palliative Care Organization](#) [NHPCO], 2018).

The hospice movement experienced significant growth and made important strides toward becoming an accepted health care entity over the next decades, particularly in the 1980s, with the creation of a federal reimbursement structure. In 1982, Congress included a provision

as part of the [Tax Equity and Fiscal Responsibility Act](#) to provide federal reimbursement for hospice services through the [Medicare Hospice Benefit](#) (Connor, 2007). Reimbursement opportunities through Medicare and commercial health insurance companies coupled with increasing societal awareness of and desire for control at life's end, created an environment ripe for hospices to grow beyond its humble beginnings as small, all-volunteer agencies into large, recognized, and profitable players in the health care biosphere (Connor, 2009).

The mission of hospice is to provide necessary and appropriate physical, emotional, and spiritual care to individuals in the final stages of terminal illness to ensure that the dying process is as comfortable and as rich as possible (NHPCO, 2018). Hospice specializes in pain and symptom management, available 24 hours a day through medical intervention as well as emotional and spiritual support. This holistic care is provided through an interprofessional team of care providers that includes physicians, nurses, home health aides, chaplains, volunteers, and social workers. Hospice emphasizes care to patients' family members as well, offering emotional and spiritual support to families throughout the duration of the patient's involvement with hospice and providing bereavement support services for 13 months following the patient's death. (NHPCO, 2018).

Hospice care is available to patients who meet admission criteria for a number of diagnoses. While cancer has historically been the most common primary diagnosis, other diseases such as end stage cardiac, circulatory, and respiratory disease, dementia and other neurological diseases, and stroke are also common primary diagnoses for hospice patients ([NHPCO Facts and Figures, 2016](#)). While there are disease-specific eligibility requirements for hospice care, patients must be certified to be terminally ill with a life expectancy of six months or less if the disease runs its normal course (NHPCO, 2018) to receive hospice services.

Hospice care is provided in whatever environment the patient resides. This may include patients' private residences, skilled nursing facilities, assisted living facilities, freestanding hospice facilities, and hospitals (NHPCO, 2018). Hospice provides various [levels of care](#) that depend upon patient needs as they change over the course of their illness. The most common level of care is routine home care in which patients and their families receive hospice services in their place of residence. General inpatient care is available for individuals with pain or symptom management issues that cannot be managed in other settings. General inpatient care may be provided in a hospital, hospice facility or skilled nursing facility that has registered nurses available 24 hours a day to provide direct care to patients. Continuous home care provides increased nursing services to manage pain and other acute medical symptoms with the goal of maintaining patients in their place of residence during a pain or symptom crisis. Continuous home care services are available from eight to 24 hours each day and must be provided primarily by nurses, but can be supplemented by hospice aid services. Finally, inpatient respite care is available to provide short-term, temporary relief for the patient's primary caregiver. Inpatient Respite Care can be provided in a hospital, hospice facility, or nursing facility that has appropriate 24 hour nursing staff available (NHPCO, 2018).

Social Work Practice in Hospice Care

Social Work as Part of the Interprofessional Team

With the implementation of the Medicare Hospice Benefit in 1982, social workers became required 'core' members of the hospice team, and as such, they must be involved to some extent, with all hospice patients and families (NHPCO, 2018). This requirement supports hospice pioneer Cicely Saunders' conviction that ideal care for the dying includes attention to

physical needs and bodily symptoms, as well as to social, psychological, emotional, and spiritual well-being.

Social workers contribute a unique set of skills and professional values that are essential to the hospice interprofessional team and to the holistic care of dying individuals and their families. Social workers are educated to practice from a person-in-environment perspective, which allows them to offer a distinct and helpful perspective to the interprofessional team regarding patients and families (Christ & Blacker, 2005). In addition, social work's educational focus on human behavior in the social environment, human diversity, as well as communication and counseling skills ([Council on Social Work Education \[CSWE\] Educational Policy and Accreditation Standards](#), 2015) uniquely equips social workers to assess and address the psychosocial needs of the dying and their families and to facilitate communication between patients and their loved ones and among interprofessional team members (Christ & Blacker, 2005). Social workers' commitment to patients' right to self-determination and informed consent ([National Association of Social Workers \[NASW\] Code of Ethics](#), 2017) prepares them to assist patients and families as well as interprofessional team members with ethical issues regarding medical treatment and end-of-life care decisions, such as those faced by the Jordan family in Case Study 2. Social workers' core values of social justice and the dignity and worth of each person (NASW Code of Ethics, 2017) equip them to advocate for humane care for the vulnerable and underserved members of society and for the provision of end-of-life services for all, regardless of social status or ability to pay. In fact, Reese and Raymer (2004) state that increased social work intervention with hospice patients and families is associated with lower hospice costs, fewer on-call visits, increased quality of care and patient satisfaction, and improved team functioning.

Social Work Assessment and Intervention in Hospice Care

Psychosocial assessment conducted by hospice social workers is an essential aspect of the comprehensive interprofessional assessment that is required to be completed for all newly enrolled hospice patients ([Center for Medicare and Medicaid Services](#) [CMS], 2018). Social workers complete an initial assessment within five calendar days of the patient's admission to hospice care (CMS, 2018) and ongoing assessments throughout the course of the individual's stay with hospice. The psychosocial assessment is used to guide care planning related to social work visit frequency and content, intervention, and referrals. The National Hospice and Palliative Care Organization (NHPCO) recognizes eleven essential elements of a comprehensive psychosocial assessment (Reese et al., 2006). These elements have remained unchanged since they were enacted more than a decade ago and are utilized to direct social work intervention with patients and their loved ones.

Awareness of Prognosis

In order to undertake the immense psychological, emotional, social, and practical issues of one's life coming to an end, patients must have some awareness of their prognosis (Cagle, Osteen, Sacco, & Frey, 2017). Consequently, hospice social workers assess the extent and scope of this awareness. Assessment may include such questions as: Have the patient and family been told by the physician of the patient's expected prognosis? Do the patient and/or family members understand the illness, its expected progression, and that it will ultimately lead to the patient's death? Do patient and/or family members display denial about the patient's terminal status? Is patient or family lack of awareness or denial about prognosis creating barriers to hospice services? While it is common for those with terminal illness and their loved ones to vacillate between denial and recognition of the patient's terminal status throughout the course of their

illness (Rando, 2000), issues of awareness and denial are important to address. This issue is certainly one that may be interfering with Mrs. Jones' struggle to discontinue treatment and to accept hospice services.

In situations in which patients and/or their loved ones display any of these issues, social workers intervene with caution and gentleness, recognizing that denial is serving some purpose to the patient or family (Reith & Payne, 2009). Social workers are present, open, and ready to listen and support when patients or families are prepared to address these issues.

End-of-Life Decisions

Because patient self-determination is a key aspect of hospice care (NHPCO, 2013) and social work ethics (NASW Code of Ethics, 2017), social workers assess patient and family desires for end of life care and treatment in conjunction with other interprofessional team members. Decisions to be addressed include treatment considerations, code status and do not resuscitate orders, artificial nutrition and hydration, medical durable power of attorney, organ or tissue donation, and funeral plans. Social workers assess and assist patients and families in exploring ethical, cultural, and religious preferences related to these decisions.

Anxiety About Death

Those who are terminally ill are likely to struggle with a variety of issues that may be characterized under the umbrella of death anxiety. These may include fear of loneliness or abandonment, fear of physical pain, fear of personal extinction, and/or fear of the unknown (Conte, Weiner, & Plutchik, 1982; Tong et al., 2016). In addition, questions and concerns about the afterlife suggest that death anxiety may intersect with spiritual issues (Reese et al., 2006) and may require the support and assistance of a spiritual counselor. Social work intervention regarding death anxiety may include counseling to clarify sources of fear or anxiety and to assist

in addressing these, referral to the hospice chaplain or the patient's own spiritual counselor, and assisting the patient in recognizing the ways in which her or his life has been meaningful and important. Reminiscence and life review activities may be especially helpful to terminal individuals in recognizing and embracing the unique meaning of their personal experiences and relationships.

Patient Suicidal Ideation

Individuals who understand that their disease process will inevitably lead to their demise may be more likely to entertain thoughts of suicide or a desire to hasten their death (Black, 2000; Quill, Back, & Block, 2016). Social workers assess for suicidal ideation on an ongoing basis and talk with patients who express suicidal thoughts to explore underlying needs or concerns.

Common concerns that may contribute to suicidal ideation among hospice patients may include unaddressed physical or psychic pain, a desire to control the circumstances of death, or guilt or distress regarding the practical, emotional or monetary costs of his or her care (Reese et al., 2006). Social workers intervene by assisting with planning for patient safety, counseling to uncover and address unresolved emotional and psychological concerns, facilitating pain and symptom control through medical staff, providing referrals for supplemental or alternative care options, addressing financial concerns and connecting patients and families with appropriate resources, and advocating with family and the interprofessional team for patient's right to self-determination to ensure maximum control at life's end.

Environmental Preferences

In keeping with hospice and social work's value regarding patients' right to self-determination, hospice social workers engage in ongoing assessment regarding individual preferences for their environment, whether they reside in their own home or in an assisted living,

extended care or hospice facility. Decisions may include preferences about bed placement in the home, access to personal and/or meaningful belongings, presence of pets, frequency, number, and length of visits from friends and family, and television, social media, and music preferences (Reese et al., 2006). Social workers explore these preferences with the individual as they unfold and evolve throughout the disease process. In addition, they advocate for patient environmental preferences with family members and the hospice interprofessional team.

Social Support

Terminally ill individuals and their loved ones routinely identify social support and meaningful relationships with friends and family as a key component of end of life care and well-being (Grassman, 2010; Munn & Zimmerman, 2006). This is supported with empirical evidence that shows that higher levels of perceived social support is correlated with lower levels of death anxiety for those with a terminal illness (Azaiza, Ron, Shoham, & Gigini, 2010). Hospice social workers recognize the impact of social support for their terminally ill patients and routinely assess support through family, friends, and caregivers. In assessing social support, social workers ask questions such as: Who does the individual identify as his or her social support system, for emotional as well as practical needs? How satisfied is the patient with his or her level of support from family, friends, and/or caregivers? Does the patient report feelings of loneliness or isolation? Would the patient benefit from a hospice volunteer as an additional source of support? Are there relationship concerns or issues that the patient would like assistance in addressing? To attend to these issues, hospice social workers may advocate for increased support from the individual's family and friends, initiate a referral for a hospice volunteer friendly visitor and/or assist with opening discussions and exploring with family and friends perceived unmet social support needs, relationship issues or communication concerns.

Financial Resources

Hospice social workers assess patient and family financial resources and needs during the initial assessment and throughout the course of the individual's stay with hospice. Financial issues assessed include presence and adequacy of health insurance coverage for hospice care, medications, medical equipment, and supplies for end-of-life care, adequacy of income and assets for housing, basic needs, and/or placement in a care facility, and concerns about loss of income due to illness or caregiving responsibilities. Social workers may intervene by assisting with accessing Medicaid or other insurance benefits, assisting with completing Family Medical Leave paperwork for the patient or caregiver's employer, coordinating referrals to financial or benefits assistance agencies, and advocating with and for patients and families for these benefits.

Safety Issues

As terminal disease progresses, hospice patients most often become less able to attend to their own needs and independently complete activities of daily living (Connor, 2009). Therefore, there may be concerns about patient safety, particularly if she or he lives alone, with a spouse or family member in fragile health, or with a spouse or family member exhibiting denial of the patient's abilities or needs (Hansen, Martin, Jones, & Pomeroy, 2015; Reese et al., 2006).

Hospice social workers, in conjunction with medical professionals, vigilantly assess patient safety within their home environment. The central question of this ongoing assessment is as follows. Does the patient have adequate support to allow her or him to remain safely in her or his current environment as the disease progresses and care needs increase? This is certainly an issue to consider for Mrs. Jones and her children in Case Study 1. It is necessary to engage in ongoing assessment and dialogue with patients and their loved ones to avoid patient or caregiver injury and to assure that patient care needs are being adequately addressed and managed.

On occasion there are those mentally competent individuals who make decisions about their care or environment that raise safety concerns among family members and/or hospice staff. In these situations, social workers are often called on to assist patients in exploring potential negative outcomes of their care choices while also advocating with family and/or the interprofessional team for patients' right to make decisions for their care. In cases where there are questions about patient competence to make such decisions, [Adult Protective Services](#) may be consulted and/or a referral made to open an investigation into the individual's competence to make his or her own care and environment decisions.

In addition to assessing presence and adequacy of care, hospice social workers assist patients and families in understanding care options such as whether they may benefit from hospice home health aides to assist with care or volunteers to provide caregiver respite for the primary caregiver, supplemental, paid in-home caregivers, and/or out of home living options. If and when the need arises for any of these care options, social workers coordinate and facilitate referrals for these services.

Because the family is considered the unit of care in hospice (NHPCO, 2016), hospice social workers are also concerned about the health and safety of the patient's primary caregiver(s). Social workers assess the willingness and ability of primary caregiver(s) to safely provide care to the patient as intensity and/or duration of care needs increase, extending beyond the physical or emotional capacity of the caregiver(s). Social workers validate the physical and emotional toll caregiving can have on caregivers, assess for caregiver stress and burnout, and encourage and support caregiver self-care.

Comfort Issues

Management of physical pain and other physiological symptoms is a central premise of hospice care (NHPCO, 2018). Hospice physicians and nurses are highly skilled in alleviating pain and other physical symptoms in a variety of ways using specialized medications administered in various manners. Hospice social workers assist with the alleviation of physical pain and symptoms as well as monitor for physical pain or symptoms during home visits and communicate any identified physical symptoms to hospice physicians and nurses for follow up. In addition, hospice social workers may assist with non-medical intervention for physical pain and symptoms by providing or teaching visualization, relaxation, or meditation techniques. Prior studies have concluded that until patients' physical pain and symptoms are managed adequately, they may be unable to work through psychological and emotional aspects of their illness, complete significant and meaningful end-of-life tasks, and satisfactorily bring relationships with loved ones to a close (Byock, 1996; Doka, 2013).

Psychosocial and spiritual dimensions influence patients' physical comfort (Reese, 2013). Consequently, an important role for hospice social workers is to assess and address the psychological and emotional comfort of their terminally ill patients. Patients often struggle with a variety of challenging emotions as they journey through the dying process and work to come to terms with their impending demise. Anger, sadness, fear, anxiety, guilt, and jealousy are considered reasonable feelings for terminally ill individuals and their loved ones and these emotions be experienced at various times and to varying degrees throughout their living-dying interval (Doka, 2013; Rando, 2000). Hospice social workers monitor patients and their loved ones for these burdensome feelings, validate and normalize them, and assist patients and their loved ones to learn and employ safe and helpful techniques to express and work through their feelings.

Complicated Anticipatory Grief

Anticipatory grief describes the experience of mourning past, present, and future losses prompted by awareness of impending death (Costello & Hargreaves, 2008; Lindemann, 1944; Rando, 2000). Losses and associated anticipatory grief may be experienced by both the terminal individual as well as her or his loved ones. Terminally ill individuals may grieve the loss of their known life and future hopes, the end of relationships with loved ones, and the progressive loss of bodily function as illness advances. Loved ones of those with terminal illness may grieve the anticipated loss of the terminally ill person, loss of plans and hopes for the future, and role loss related to the relationship with the ill individual (Doka, 2014; Rando, 2000). Anticipatory grief typically parallels post death grief in its symptomatology and can include physical, emotional, cognitive, and spiritual responses (Doka, 2014; Rando, 2000; Simon, 2008). At times, terminally ill individuals or their loved ones struggle with psychological and emotional concerns that extend beyond what is characteristically noted and that cannot be resolved adequately. Factors that may interfere with successful working through of anticipatory grief include significant anger or depression related to the terminal illness, guilt regarding past actions, and unresolved spiritual questions or struggles (Reese et al., 2006). Any of these unresolved concerns may prevent the individual from dying peacefully. Hospice social workers intervene in these situations by inquiring about patient and family beliefs and concerns about the meaning of the patients' illness and provision of support and counseling as they seek meaning in their life and their death. In addition, social workers facilitate opportunities for terminally ill individuals to resolve past conflicts or difficult relationship issues and to complete worldly affairs to their satisfaction (Rando, 2000, Reese et al., 2006).

Spirituality

From a holistic, existential perspective, spirituality refers to the continuously unfolding energy that gives meaning and purpose to one's existence (Stephenson, Drauker, & Martsof, 2002). Spirituality then, is less about belief systems and organized religion and more about fundamental human questions regarding meaning and purpose in life and connection to others and to someone or something greater than oneself. Consequently, spirituality applies to everyone, irrespective of religious or non-religious path (O'Neill & Kenny, 1998; Reese, 2013). Hospice social workers, along with other interprofessional team members, assess patients' personal spiritual beliefs and meaning and note any spiritual distress. Social workers may assist patients in exploring these spiritual beliefs and meanings and encourage them to resolve any spiritual distress. Social workers also refer patients to spiritual care services through the hospice chaplain or through patients' desired spiritual care advisor.

Controversial Issues at Life's End: Medical Decision Making

Advances in health care technology provide physicians and the medical community with the ability to extend life in ways that would have seemed unattainable in the past. While these advances have offered hope and healing to many seriously ill individuals, they have come with consequences. Health care decisions at the end of life can be difficult and fraught with emotional and ethical challenges for patients and their loved ones. Three end of life decisions that occur frequently and can be especially difficult for hospice patients and their loved ones include advance directives and appointment of a patient advocate, artificial nutrition and hydration, and cardiopulmonary resuscitation. Hospice social workers, along with medical staff, assist patients and families to understand, consider, and make decisions regarding these challenging issues.

Advance Directives and Appointment of Patient Advocate

The [Patient Self Determination Act of 1990](#) is a Federal law that impacts all health care agencies receiving federal funds. In brief, the Act requires that health care agencies provide all mentally competent adults with information regarding their right to accept or refuse treatment, to complete advance directives, and to appoint a patient advocate. Advance directives, sometimes referred to as health care directives, are written statements that advise loved ones and the medical community of the individual's wishes for medical care. A patient advocate is a mentally competent adult appointed by an individual to make medical decisions on her or his behalf if and when the person is no longer able to do so due to mental incapacitation. Required legal forms to complete advance directives and to appoint a patient advocate vary state to state, but generally are available on line at no cost and do not require a lawyer in order to enact them.

Advance directives can be helpful for loved ones of terminally ill individuals as they can alleviate the conjecture, emotional struggle, and guilt that can accompany end-of-life decision making. Hospice social workers have discussions with and provide education to patients and families about the purpose and benefit of advance directives and appointment of a patient advocate. They also initiate and facilitate conversations to assist patients and families to think through their wishes related to medical decision making, and assist patients and families with completing and distributing these documents.

Artificial Nutrition and Hydration

When an individual can no longer take food or fluids by mouth, physicians sometimes recommend a feeding tube to compensate for this inability. Feeding tubes are inserted and nutrition administered in various ways, depending on individual patient circumstances and medical provider best practice philosophy (Dunn, 2001). Fluids and medication may also be

administered through an intravenous (IV) line inserted in to an individual's arm. Feeding tubes and IV hydration have been helpful, lifesaving interventions for many individuals in recovery from serious illness or accident (Dunn, 2001). However, for those with terminal illness in which curative treatments are futile, the use of artificial means to feed and/or hydrate patients becomes more complicated and there are a diversity of opinions about the benefits and burdens of these interventions (Dunn, 2001; van deVathorst, 2014).

Those who advocate for the use of artificial nutrition and hydration for terminally ill individuals, such as Mr. Jordan's daughter Bonnie and son Jack, do so for various reasons. They may believe that food and fluids administered by any means necessary will improve the terminally ill individual's quality of life and help her or him to 'feel better' (van de Vathorst, 2014). They may be concerned that to not agree to artificial nutrition and hydration is to 'give up' on the terminal individual and to admit that the individual's disease will indeed result in her or his death (Brody et al., 2011; Dunn, 2001; van de Vathorst, 2014). They may believe that food and water are basic human rights that should not be denied anyone, regardless of their medical condition or proximity to death (Dunn, 2001). They may believe that to deny artificial food and fluids will lead to physical suffering as the terminally ill person 'starves to death' (Dunn, 2001). Those who advocate against the use of artificial nutrition and hydration at life's end typically stress that there is no evidence that artificial nutrition at the end of life improves quality of life or extends life expectancy and that failure to implement artificial nutrition and hydration does not lead to undue physical suffering (Dunn, 2001; van de Vatvorst, 2014). These advocates, such as Mr. Jordan's son David, point to the burdens associated with the administration of artificial food and fluids at life's end. Burdens may include infection at the site of the feeding tube insertion, increased fluid in the lungs and throat that can make breathing difficult, pressure around tumors

leading to increased pain, and increased fluid retention in the hands and feet (Dunn, 2001; van de Vatvorst, 2014; Winter, 2000). In addition, they suggest that to characterize withholding or withdrawing artificial nutrition and hydration as ‘starving’ the dying individual is erroneous. Whatever pain or discomfort that may be associated with malnutrition related to the inability to eat normally is immaterial as the individual will be impacted by dehydration long before any effects of inadequate nutritional intake take effect (Dunn, 2001). Further, there is robust medical evidence that dehydration in the end stages of terminal illness is a natural and compassionate way to die (Dunn, 2001; Van de Vatvorst, 2011). Choosing not to introduce or continue artificially administered food and fluids is, in essence, choosing not to extend the dying process. Hospice social workers, along with the medical team, assist terminally ill patients and their loved ones to navigate this perplexing and emotionally-laden issue. They offer education about the costs and benefits of artificial nutrition and hydration and provide counseling to assist patients and their families to sort out their thoughts and feelings as well as the personal, cultural, and religious values that underlie these.

Cardiopulmonary Resuscitation

Cardiopulmonary resuscitation (CPR) is an emergency life-saving sequence of procedures utilized when an individual’s heart and/or breathing stops. Since its development in the 1960s, CPR has become standard medical practice and has saved millions of lives. Healthy individuals and those with few medical issues generally desire CPR if and when their heart and/or breathing ceases in order to be granted every opportunity for being restored to their prior functioning. In addition, the administration of CPR is the default procedure in acute care settings on all patients who experience heart or breathing failure unless there are physician orders restricting its use (Chavez, Einav, & Varon, 2017; Dunn, 2001). When an individual is

terminally ill, however, the desire for and practice of administering CPR typically becomes more ambiguous.

When an individual is in failing health due to a progressive or terminal illness, the heart and lungs will ultimately fail as a result of that illness. In these circumstances, the chances of survival after the administration of CPR is less than two percent (Dunn, 2001). In addition, if CPR is successful with these individuals, success will be temporary as their weakened condition will again lead to subsequent heart and breathing failure. In such cases, individuals may request a ‘do not resuscitate’ (DNR) or ‘allow natural death’ (AND) order, expressing their wish to receive no resuscitation attempts when their heart and/or breathing ceases. This order must be given by a physician.

Requesting or consenting to a DNR or AND order, even for critically or terminally ill individuals, can be a complicated and emotionally complex issue. Sensitive and instructive dialogue between and among the ill individual (if possible), their loved ones, and the health care team are prerequisite to making the decision to forgo resuscitation attempts and request DNR or AND status. Hospice social workers assist with the process of helping terminally ill individuals and their loved ones to understand the benefits and burdens of utilizing CPR and to unravel their thoughts, feelings, and values related to resuscitation.

Controversial Issues at Life’s End: Assisted Death

Over the past several years, assisted death has become an increasingly complex issue, particularly in the context of hospice care. Moral and religious views, political agendas, and strongly held feelings and belief systems about life, death, and the freedom to choose have steeped the debate about assisted death in controversy. Those who support assisted death argue that the right to control one’s body and care decisions at life’s end is imperative and should not

be proscribed. Those who oppose assisted death cite concerns about coercion and caution against a slippery slope of an ever expanding list of vulnerable individuals who ‘qualify’ for assisted death (Kussmaul, 2017; Quill et al., 2016). The National Hospice and Palliative Care Organization has historically and consistently asserted that hospice neither prolongs nor hastens death and has unwaveringly affirmed its commitment to the value of life (NHPCO, 2018). This stance has traditionally acted to guide hospice agencies and staff in their conversations with terminal patients and their family members regarding inquiries about assisted death. However, the legalization of physician assisted death in several states has created increasing uncertainty and debate among hospice organizations and staff. Currently, six states, Oregon, Washington, Vermont, California, Colorado, and Hawaii, as well as the District of Columbia have legalized physician assisted death through ballot initiative or legislative action ([Death with Dignity](#), 2018; Emanuel, Onwuteaka-Philipsen, Urwin, & Cohen, 2016). For social workers, personal feelings and belief systems about this issue also necessarily intersect with the profession’s commitment to patients’ right to self-determination (NASW Code of Ethics, 2017). In order to navigate the complexity of this issue with professionalism and balance, social workers are encouraged to wrestle with their personal beliefs and feelings about assisted death and to understand and comply with policies within their individual practice locations.

Chapter Summary

The mission of hospice is to provide necessary and appropriate physical, emotional, and spiritual care to individuals in the final stages of terminal illness through an interprofessional team of caregivers. Social workers are an integral part of this team as they provide assessment, support, counseling, advocacy, and resource referral related to a variety of end-of-life issues.

Chapter 14 Review Questions

1. The concept of hospice was first introduced in the United States in what year?
 - a. 1953
 - b. 1961
 - c. 1963
 - d. 1975

2. The four levels of care in hospice care include
 - a. routine home care, continuous care, general inpatient care, and respite care
 - b. routine home care, facility care, hospital care, and respite care
 - c. family based care, facility based care, hospital based care, and hospice facility based care
 - d. home care, assisted care, inpatient care, and respite care

3. Social work assessment and intervention includes all of the following areas except
 - a. End of life decisions
 - b. Anxiety about death
 - c. Spirituality
 - d. Life expectancy

4. A mentally competent adult appointed by an individual to make medical decisions on her or his behalf if and when the person is no longer able to do so due to mental incapacitation is referred to as a
 - a. Patient Advocate
 - b. Patient Activist
 - c. Primary Caregiver
 - d. Primary Advocate

5. Which of the following are NOT true of Cardiopulmonary Resuscitation?
 - a. It is standard medical practice when someone's heart and/or breathing stops
 - b. It is the default procedure in acute care settings
 - c. It is a helpful and desired intervention for hospice patients
 - d. Decisions about CPR are emotionally laden and complicated for hospice patients

Additional Exercises

1. Explore the [National Hospice and Palliative Care Organization](#) website. What additional information about Hospice care can you glean from exploring this site?

2. Download the [National Hospice and Palliative Care Facts and Figures Report](#). Explore various aspects of the report including who receives hospice care, how much care was provided, and who provides care.

3. Search for hospices that provide care in your area of residence. How many are there? Can you find ways in which the provision of service differs hospice to hospice?
4. Explore the legal status of physician assisted death in your state. How does the legal precedent in your state align or conflict with your personal thoughts and feelings about physician assisted death? How might you respond to a hospice patient inquiring about physician assisted death?

References

- Azaiza, F., Ron, P., Shoham, M., & Gigini, I. (2010). Death and dying anxiety among elderly arab muslims in Israel. *Death Studies*, 34(4), 351-364.
- Beredsford, P., Adshead, L., & Croft, S. (2007). *Palliative care, social work, and service users: Making life possible*. Philadelphia, PA: Kingsley.
- Black, S.D. (2000). Assessing and managing depression in the terminally ill patient. *Annals of Internal Medicine*, 132(3), 209-218.
- Brody, H., Hermer, L.D., Scott, L.D., Grumbles, L.L., Kutac, J.E., & McCammons, S.D. (2011). Artificial nutrition and hydration: The evolution of ethics, evidence, and policy. *Journal*
- Byock, I. (1997). *Dying well: Peace and possibilities at the end of life*. New York: Riverhead Books.
- Cagle, J.G., Osteen, P., Sacco, P. & Frey, J.J. (2017). Psychosocial assessment by Hospice social workers: A content review of instruments from a national sample. *Journal of Pain and Symptom Management*, 53(1), 40-48.
- Centers for Medicare and Medicaid Services (2018). Baltimore, MD. Retrieved from <http://www.cms.gov/>
- Chavez, L.O., Einav, S., & Varon, J. (2017). When terminal illness is worse than death: A multicenter study of health-care providers' resuscitation desires. *American Journal of Hospice and Palliative Medicine*, 34(9), 820-824.
- Christ, G.H., & Blacker, S. (2005) Series introduction: The profession of social work in end-of-life and palliative care. *Journal of Palliative Medicine*, 8 (2), 415-417.
- Connor, S. R. (2009). *Hospice and palliative care: The essential guide*. New York, NY: Taylor & Francis.
- Connor, S.R. (2007) Development of hospice and palliative care in the United States. *Omega*, 56 (1), 89-99.
- Conte, H., Weiner, M., & Plutchik, R. (1982). Measuring death anxiety: Conceptu psychometric, and factor-analytic aspects. *Journal of Personality and Social Psychology*, 43(4), 775-785.
- Costello, J. & Hargreaves, S. (2008). Anticipatory grief: Some implications for social work practice in working with families facing impending loss. *Social Work in Action*, 10, 45-54.

- Council on Social Work Education (2015) *Educational Policy and Accreditation Standards*. Alexandria, VA. Retrieved from: <http://www.cswe.org>
- Death with Dignity (2018). Portland, OR. <https://www.deathwithdignity.org/>
- DiTullio, M., & MacDonald, D. (1999). The struggle for the soul of hospice: Stress, coping and change among hospice workers. *American Journal of Hospice and Palliative Care*, 16 (5), 641-655.
- Doka, K. J. P. (2014). *Counseling individuals with life threatening illness*, (2nd ed.). New York: Springer Publishing
- Dunn, H. (2001). *Hard choices for loving people: CPR, artificial feeding, comfort care, and the patient with life threatening illness*. Herndon, VA: A & A Publishers.
- Emanuel, E.J., Onwuteaka-Philipsen, B.D., Urwin, J.W., & Cohen, J. (2016). Attitudes and practices of euthanasia and physician assisted suicide in the United States, Canada, and Europe. *Journal of the American Medical Association*, 316(1), 79-90.
- Grassman, J. (2010). The chronically ill and end-of-life care. In Atwood, J.D. & Gallo, C. (eds). *Family Therapy and Chronic Illness*. New Brunswick, New Jersey: Aldine Transaction.
- Hansen, A.G., Martin, E., Jones, B.L., & Pomeroy, E.C. (2015). Social work assessment notes: A comprehensive outcomes-based hospice documentation system. *Health & Social Work*, 40(3), 191-200.
- Kussmaul, W.G. (2017). The slippery slope of legalization of physician-assisted suicide. *Annals of Internal Medicine*, 167(8), 595-596.
- Lindemann, E. (1944). The symptomatology and management of acute grief. *American Journal of Psychiatry*, 101, 141-148.
- Noe, K., Smith, P.C., & Younis, M. (2012) Calls for reform to the US Hospice system. *Aging International*, 37, 228-237.
- National Association of Social Workers (2017) *Code of Ethics for Social Workers*. Washington, DC. Retrieved from: <http://www.socialworkers.org/pubs/code/code.asp>
- National Hospice and Palliative Care Organization (2018). Alexandria, VA. <http://www.nhpc.org/about/hospice-and-palliative-care>
- National Hospice and Palliative Care Facts and Figures: Hospice Care in America. (2016) Alexandria, VA.

- Munn, J. & Zimmerman, S. (2006). A good death for residents in long term care: Family members speak. *Journal of Social Work in End-of-Life and Palliative Care*, 2, 45-59.
- O'Neill, D.P., & Kenny, E.K. (1998). Spirituality and chronic illness. *Images: The Journal of Nursing Scholarship*, 30(3), 275-281.
- Patient Self Determination Act of 1990, P.L. 101-508, 104 Stat. 1388 (1990).
- Puterman, E., DeLongis, A., & Pomak, G. (2010). Protecting us from ourselves: Social support as a buffer of trait and state rumination. *Journal of Social and Clinical Psychology*, 29(7), 797-820. NOT USED AS OF SOCIAL SUPPORT SECTION
- Quill T.E., Back A.L., & Block S.D. (2016). Responding to patients requesting physician-assisted death: Physician involvement at the very end of life. *Journal of the American medical Association*, 315(3), 245–246.
- Rando, T.A. (2000). *Clinical dimensions of anticipatory mourning: Theory and practice of working with the dying, their loved ones, and their caregivers*. Champagne, IL: Research Press.
- Reith, M. & Payne, M. (2009). *Social work in end-of-life and palliative care*. Chicago, IL: Lyceum Books.
- Reese, D.J. (2013). *Hospice social work*. New York: Columbia University Press.
- Reese, D.J., & Raymer, M. (2004) Relationships between social work involvement and hospice outcomes: Results from a national hospice social work survey. *Social Work*, 49 (3), 415-422.
- Reese, D.J., Raymer, M., Orloff, S., Gerbino, S., Valade, R., Dawson, S., Butler, C., & Wise-Wright, M., & Huber, R. (2006). The Social Work Assessment Tool (SWAT). *Journal of Social Work in End-of-Life and Palliative Care*, 2(2), 65-95.
- Saunders, D.C. (2001) Social work and palliative care: The early history. *British Journal of Social Work*, 31, 791-799.
- Simon J.L. Anticipatory grief: recognition and coping. *Journal of Palliative Medicine*. 2008; 11(9):1280-1281.
- Stephenson, P.S., Draucker, C.B., & Martsolf, D.S. (2002). The experience of spirituality in the lives of hospice patients. *Journal of Hospice and Palliative Nursing*, 5(1), 51–58.
- Tong, E., Deckert, A., Gani, N., Nissim, R., Rydall, A., Hales, S., Rodin, G., & Lo, C. (2016). The meaning of self-reported death anxiety in advanced cancer. *Palliative Medicine*, 20(8), 772-779.

Winter, S.M. (2000). Terminal nutrition: Framing the debate for the withdrawal of nutritional support in terminally ill patients. *American Journal of Medicine*, 109, 723-726.