

Palliative and End-of-Life Care

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The vast majority of Americans want to die at home, surrounded by family, free of pain and other distressing symptoms, and treated with respect, so they can die with dignity. The reality is often very different. The majority of American die in institutions, including hospitals and nursing homes (Institute of Medicine [IOM], 2014). Those in hospitals may spend days or weeks isolated in an intensive care unit. The cost of caring for patients at the end of life is financially and emotionally costly for families. Palliative care provides an alternative to this reality. In this chapter, we present the benefits of palliative care and the role of palliative social workers.

DEFINITION OF PALLIATIVE CARE

Palliative care is specialized care for persons with serious illness. The World Health Organization (WHO) provides a comprehensive definition of palliative care:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO, 2017)

The aim of palliative care is to improve quality of life for the patient and family. Palliative care specialists facilitate communication among the patient, health care providers, and family members to better understand the illness and goals of care. They manage complex physical and emotional symptoms, including pain, depression, and fatigue, and coordinate care transitions across health care settings. The purpose of these interventions is to help patients and family members make informed decisions about their care in a timely manner, manage symptoms, and maximize functional ability (Center to Advance Palliative Care, 2017). Palliative care provides support to help families cope during the patient's illness and after the patient's death. It is appropriate for any life-limiting diagnosis, including cancer, cardiovascular disease, respiratory illness, neurological illness, or dementia. Eight domains of palliative care were established by the National Consensus Project for Quality Palliative Care (NCP): Structure and Processes of Care,

Physical, Psychological, Social, Spiritual, Cultural, End-of-Life Care, and Ethical and Legal (National Quality Forum, 2006).

PALLIATIVE CARE CONTINUUM

Palliative care is beneficial and appropriate at all stages of a serious illness. Figure 9.1 illustrates the palliative care continuum (adapted from Lynn, 2005; Mudigonda & Mudigonda, 2010). Ideally, palliative care is initiated at the time of diagnosis and is delivered simultaneously with curative care. As the illness progresses, the amount and scope of palliative care services increases. In the final stage of the disease, when curative care is no longer wanted by the patient or no longer beneficial, hospice care should be considered.

Hospice care is provided in the final stage of a terminal illness. The philosophy of hospice is that death is a natural process and individuals have the right to die free of pain and with dignity (National Hospice and Palliative Care Organization, 2017). While hospice incorporates palliative care practices, the timing, setting, and payment mechanism of hospice differs from palliative care. Currently, the Medicare Hospice Benefit, which pays for almost 90% of hospice care in the United States, stipulates that death is expected within 6 months and that curative care must be discontinued. Curative treatment is allowed only for potentially curable conditions, such as bladder infections, if the patient chooses, with brief hospital stays if necessary. A current trial allows Medicare beneficiaries to receive hospice-like support services from hospice providers while receiving curative treatment (Centers for Medicare and Medicaid Services [CMS], 2017). The CMS is evaluating whether this improves quality of life and care, increases patient satisfaction, and reduces expenditures.

The Medicare Hospice Benefit covers services provided by physicians, nurses, social workers, chaplains, and aides, and medications, equipment, grief support following a death, and other services deemed appropriate by the hospice provider. In 2014, 1.6 to 1.7 million patients received hospice services (National Hospice and Palliative Care Organization, 2016). The median length of stay in hospice was 17.4 days, with 35.5% staying less than a week.

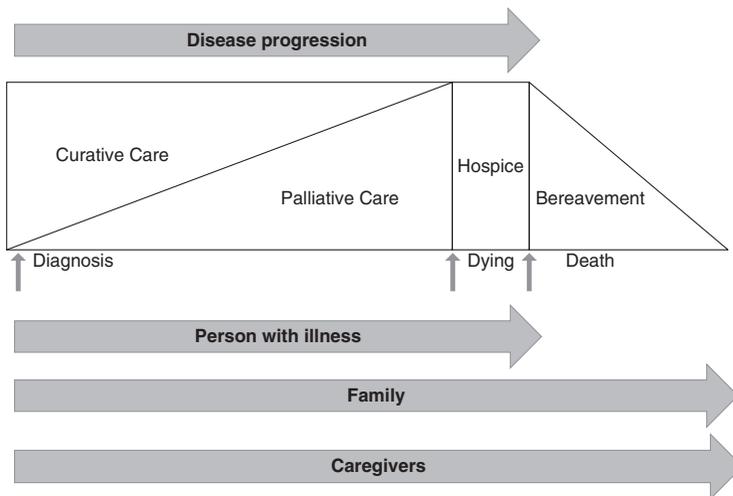


Figure 9.1 Continuum of palliative care.

Source: Adapted from Lynn, J. (2005). Living long in fragile health: The new demographics shape end of life care. *The Hastings Center Report, Spec No, S14–S18*; Mudigonda, P., & Mudigonda, T. (2010). Palliative cancer care ethics: Principles and challenges in the Indian setting. *Indian Journal of Palliative Care, 16*(3), 107–110.

PALLIATIVE CARE SETTINGS AND MODELS

Palliative care is delivered in a wide range of settings and with different models of care. These settings include: inpatient facilities, including intensive care units (ICUs) and emergency departments, outpatient settings, community-based settings, long-term care facilities, and home-based settings. In 2015, 56.0% of days of hospice care were received at a private residence, 41.3% in a nursing facility, 1.3% in a hospice inpatient facility, 0.5% in an acute care hospital, and 0.9% in another location (National Hospice and Palliative Care Organization, 2017). Palliative and hospice care may also be delivered by telehealth (Bishop, Flick, & Wildman, 2015). Regardless of the setting, hospice services are available 24 hours a day, 7 days a week.

There are many models for delivering palliative care. Palliative care is best delivered by an interdisciplinary team that integrates the physical, psychological, social, and spiritual aspects of care. The core team includes a physician, nurse, social worker, and chaplain. In many settings, the team may be augmented by pharmacists, physical therapists, occupational therapists, arts therapists, massage therapists, and other complementary and alternative care practitioners. Embedded programs are a newer model, in which a palliative care specialist or team is employed by a primary specialty, such as oncology, to provide palliative care. Volunteers may play an important role in supporting the patient and family, particularly in hospice care. In smaller facilities or those with fewer resources, palliative care may be delivered by only a palliative care physician or nurse, or by generalist-level palliative care practitioners.

ADVANCE DIRECTIVES

An advance directive may be one of several types of legally executed documents that contain an individual's instructions for the provision, withholding, or withdrawal of life-sustaining treatment. Every adult, regardless of health status, should have a health care agent (HCA) and a living will because it is often not predictable when these will be needed. Making decisions in a medical crisis is stressful and may not be in accordance with the patient's preferences. The different types of advance directives are as follows.

Living Will

This is a legal document that states the medical treatments that the individual would, and would not, want if the individual is unable to make or communicate such decisions. These treatments might be used to prolong life or to bring symptom relief, and may include resuscitation, mechanical ventilation, nutrition and hydration, tube feeding, dialysis, antibiotics or antiviral medication, diagnostic tests, surgery, transfusions, and comfort care.

Health Care Agent (aka Health Care Proxy, Health Care Surrogate, Health Care Power of Attorney, Durable Power of Attorney)

This is a person named by the patient to make medical decisions, according to the patient's wishes, when the patient is no longer able to communicate. The HCA may be authorized to consent or withhold consent for medical treatment, hire or fire medical personnel, and make decisions about medical facilities. The HCA cannot override the patient's preferences if the patient is able to make and communicate treatment decisions.

Do Not Resuscitate (DNR), Do Not Attempt Resuscitation (DNAR) or Do Not Intubate (DNI) Order

These may be noted in the medical record apart from a living will, or these preferences may be included in the living will. Increasingly, Allow Natural Death (AND) is being used instead of DNR.

Medical Orders for Life-Sustaining Treatment

Medical Orders for Life-Sustaining Treatment (MOLST) is a medical order in which the physician records patient preferences for medical treatment wanted and not wanted. MOLST is appropriate for persons likely to be in their final year of life. It is portable and stays with patients as they move through different care settings. MOLST differs from a living will because it is a medical order that is actionable and can be followed by doctors and first responders (e.g., emergency medical technicians, police, and fire departments; Hickman, Sabatino, Moss, & Nester, 2008). In some states, this is called Physician Orders for Life-Sustaining Treatment (POLST).

Social workers can help facilitate conversations about preferences for treatment at end of life between patients and health care agents. Advance directives should be reviewed and revised as needed when there is a new diagnosis, change in prognosis, the patient's wishes change, or a new HCA is appointed.

PRACTICE

Competencies and Certification

The National Association of Social Workers (NASW) established standards for palliative social work in 2004 (NASW, 2004), but core social work competencies in the eight domains of palliative care have not been developed. The Clinical Practice Guidelines for Quality Palliative Care were published by the National Quality Forum (National Quality Forum, 2006). This report identifies the skills required to manage symptoms and needs of seriously and terminally ill patients.

NASW Advanced Certified Hospice and Palliative Social Worker (ACHP-SW)

This credential captures the knowledge, skills, and abilities of specialist-level social workers in hospice and palliative care settings, using a standardized measurement process (NASW, 2015). Eligibility requirements include: masters of social work (MSW) degree, at least 2 years of supervised post-MSW practice in hospice or palliative care, weekly supervision by a social worker, positive ratings of knowledge applied to practice and performance, and at least 20 hours of continuing education in hospice and palliative care.

Social Work Hospice and Palliative Network (SWHPN) Palliative Care Certification

In 2016, SWHPN initiated development of a certification for specialist-level palliative social workers that parallels medicine and nursing. The certification will include an examination assessing knowledge and skills required for specialty practice. Specialty certification in palliative social work will raise the standard of practice and contribute to professional and public confidence in certified palliative social workers.

Generalist-Level Palliative Social Work Core Competencies

Not all seriously and terminally ill individuals will need, or have access to, specialty palliative care. This means that social workers in all health care settings, as well as in social service settings, need generalist-level palliative care skills. The knowledge, skills, and competencies that reflect best practices in generalist-level palliative social work have not been established, nor have core competencies been defined. The goal of the National Consensus Project to Define Generalist-Level Core Competencies, led by the MJHS Institute for Innovation in Palliative Care, is to define generalist-level palliative social work competencies in the eight domains of palliative care.

Education

Widely accepted palliative care curricula tied to competency acquisition in MSW programs do not exist. Few MSW programs have specialty palliative social work electives or content on palliative care in required or elective courses (Berkman & Stein, 2017). The SWHPN initiative will develop specialty-level curricula and the National Consensus Project to Define Generalist-Level Core Competencies will develop curricula for post-MSW social workers in generalist palliative care.

Role of the Social Worker on the Interdisciplinary Team

Palliative care is usually delivered by an interdisciplinary palliative care team for patients requiring specialist expertise. Physicians have primary responsibility for pain and symptom management. They assist the primary health care providers, patient, and/or family in decision making and medical management. Nurses focus on pain and symptom control, and may also address psychological, social, and spiritual well-being. Chaplains assess the spiritual needs of the patient and family and discuss spiritual and emotional distress, while advocating for care that fits the patient's spiritual values and beliefs.

Social workers are most likely to view the patient and family in the context of their micro and macro environment, taking into account their psychosocial history, family dynamics, and culture. Their responsibilities include: completing a biopsychosocial-spiritual (BPSS) assessment; assisting with advance care planning, goals of care, and completion of advance directives; developing and implementing a comprehensive social care plan; educating the patient and family; providing support and counseling; enhancing communication within and between the family, the interdisciplinary team, primary caregivers, and the health care system; advocating for the patient and family with the palliative care team and primary caregivers; assisting the patient and family in navigating medical and social service systems; and assisting in securing benefits and services (Stark, 2011). Social workers participate in, and may lead, the family meeting. The social worker has a role in pain and symptom management and in resolving ethical issues. An important role of the palliative social worker is providing support and counseling to patients and family members. Patients and families facing life-threatening illness often experience psychological, social, physical, spiritual, and/or financial problems. Attention to social networks, culture, finances, communication, and access to services is enhanced by the social work focus and expertise in patient, family, and social systems (Altilio, Otis-Green, & Dahlin, 2008).

Clinical Skills

Palliative social workers are specialized in assisting patients and families with the complex and challenging tasks encountered in advanced and terminal illness.

Assessment

Assessment is often the first step in working with a client and/or family members. Palliative social workers are trained in conducting a BPSS assessment. In addition to assessing the social, psychological, financial, and legal domains, social workers also assess the physical and spiritual domains. Physicians or nurses should conduct a detailed physical assessment, and chaplains a spiritual assessment, but social workers should also include these domains. This facilitates a holistic view of the patient and family, and a comprehensive approach to care planning. Social workers play an important role in pain and symptom management, and in responding to spiritual needs. Risk and protective factors are identified during the assessment process. Risk factors may include lack of social support, financial strain, depression, or declining health. Protective factors may include strong social support, adequate health insurance, a health care agent who understands the patient's preferences, or stable health.

The *physical* domain includes: functional limitations; physical symptoms, such as pain, fatigue, and dyspnea; mental status; and sexual health. The *psychological* domain includes: level of distress; depression, anxiety, and other syndromes; internal resources; problem-solving skills; and quality of life. The *social* domain includes: external resources; adequacy and availability of support; employment history; and family functioning. The *spiritual* domain includes: religious affiliation; spiritual values and beliefs; spiritual history and behavior; and spiritual well-being. The *financial* domain includes: insurance status; income; access to other financial resources; and debt burden. The *legal* domain includes: will and estate planning; advance care planning; and durable power of attorney.

There are tools available for conducting a comprehensive assessment (Reese et al., 2006) and for assessing specific domains, such as spirituality (Nelson-Becker, Nakashima, & Canda, 2006) or symptoms within a domain, such as depression (Kroenke & Spitzer, 2002). Most providers of palliative care have an assessment tool or protocol for social workers to use. The assessment tool should not be used as a checklist, but rather as a guide for a comprehensive assessment of patient risk and protective factors. A proper assessment process requires a high skill level.

Communication

Good communication skills are particularly important in palliative care, where anxiety, fear, and low health literacy may make comprehension by clients more challenging. Social work communication skills include listening empathically; tailoring information to the level of patients and caregivers; assessing, organizing, and interpreting patient and family data; and more (Glajchen & Gerbino, 2016). Physicians are most likely to inform patients of a serious diagnosis, but social workers have an important role in helping patients understand and cope with the diagnosis, prognosis, and treatment. Patients may not understand their disease, the prognosis, expected symptoms, side effects of treatment, and how this may affect their life. Social workers allow patients time to process difficult information and to connect with the emotional aspect of this information. Often, the patient or family does not fully comprehend what was said due to the overwhelming emotions that they experience upon receiving this information.

Palliative social workers can help clarify the issues for the patient and family. This requires that social workers understand the patient's medical condition and prescribed treatments. The social worker often starts by asking the patient and family about their understanding of what the physician has told them. This is a good starting point for correcting misunderstandings, discussing the meaning of the information, answering questions, addressing concerns, and offering support, benefits, and services. Patients are

sometimes labeled by health care providers as non-adherent or difficult. Social workers often play the role of eliciting the patient's or family's concerns, communicating these to the team, and advocating for the patient and family when appropriate.

Advance Care Planning

Advance care planning involves making decisions about the care that is preferred by the patient. This allows the HCA and health care providers to understand the patient's wishes if the time comes when the patient can no longer communicate. Advance care planning is not limited to completing a living will, MOLST, or DNR. It is a process of understanding the patient's values, what gives his or her life meaning, and the types of treatment the patient would, and would not, want under different circumstances (Berlinger, Jennings, & Wolf, 2013). This requires multiple in-depth conversations with the patient and the family, allowing time for questions and discussing whether the treatment options are aligned with their goals of care, values, and preferences. These conversations should be repeated when necessary, and always when the medical condition or treatment options change.

Shared decision making is a patient-centered approach often used by palliative care specialists. It is a process in which patients, family members, and health care providers determine the most appropriate treatment or care choices together (Barry & Edgman-Levitan 2012). Shared decision making is respectful of patient preferences, needs, and values (Committee on Improving the Quality of Cancer Care: Addressing the Challenges of an Aging Population, Board on Health Care Services, and IOM, 2013). It is particularly important when there is more than one treatment option and no one option is clearly advantageous (National Learning Consortium, 2013).

The physician is most qualified to discuss prognosis and treatment, and therefore typically initiates the advance care planning discussion. These discussions may involve the primary caregivers and/or the palliative care physician. Social workers and other members of the palliative care team often participate in these discussions.

Family Meeting

The purpose of the family meeting is to address the patient's diagnosis and prognosis, the goals of care, and patient and family needs and preferences. It is a forum to assess the family's strengths and needs, make joint medical decisions, and develop a plan of care. Some or all of the interdisciplinary team attends the family meeting. The patient should participate whenever possible, either in person or by phone. The family meeting facilitates communication and strengthens the therapeutic alliance between the team and the family. It is a safe space to process emotions and can provide validation for the caregiver's concerns and roles. Technology, including videoconferencing and Skype, can be used to allow participation from family members who are not able to be in the room.

A family meeting should be held under any of these circumstances: change in medical status; major decline in functional status; transition in care; patient aged 80 years or older; two or more life-threatening comorbidities; mortality risk greater than 25%; when tracheotomy, ventilator, or feeding tube are being considered; within 72 hours of admission to the ICU; to introduce hospice; when there is family conflict, distress, or crisis; extended hospital stay; lack of a HCA; new prognostic information; advance care planning or discharge planning is necessary; or when there is an ethical dilemma (Billings, 2011; Hudson, Quinn, O'Hanlon, & Aranda, 2008). The family meeting should not be a one-time intervention. Changes in prognosis or goals of care require additional meetings.

There are three phases to the family meeting: preparation, the talk, follow-up. In the *preparation* phase, some or all of the team plans the meeting, reviews the medical chart, contacts current and former care providers for useful information and invites them to

the meeting when appropriate, and arranges the meeting space to foster participation. Decisions made at this phase include who will lead the meeting, who will speak for the family, whose agenda will be followed, and who will summarize the meeting.

The *talk* portion of the meeting begins by reviewing the purpose of the meeting and the participants. The agenda is reviewed and revised as necessary (Hannon, O'Reilly, Bennett, Breen, & Lawlor, 2012). The providers assess family resiliency, vulnerability, social support, cultural beliefs, risk factors, and decision-making style. Support and validation of caregivers is provided. Recommendations for care are made. Providers make sure that the patient and family have a clear understanding of treatment choices and are included in decision making.

The *follow-up* phase entails offering support services (including social work, patient advocacy, ethics consultation, or palliative care), summarizing the meeting and action plan, and developing a follow-up plan. Providers check in with the patient and family about whether the meeting achieved their goals and whether anything important was omitted. Providers debrief after the meeting.

Psychosocial Interventions and Supportive Counseling

One of the most important roles of the palliative social worker is providing support and counseling to patients and family members (NASW, 2004). Among the most widely used approaches in palliative care are meaning-based therapy (Breitbart et al., 2012) and dignity therapy (Chochinov, 2012). Meaning-based therapy is rooted in the work of Viktor Frankl (2006) and posits that life has meaning, even in the most difficult circumstances. Dignity therapy is a brief intervention with the goal of helping terminally ill patients and family members maintain a sense of dignity by addressing psychological, spiritual, and existential challenges.

Social Work Role in Pain and Symptom Management

Social workers have an important role to play in pain and symptom management (Blacker & Christ, 2011). The dimensions of the pain experience and suffering affect more than physical suffering. They also include the emotional, cultural, social, familial, and spiritual domains. A holistic approach to pain and symptom management requires that all of these domains be addressed in treating distressing symptoms, and that each member of the interdisciplinary team contributes to the assessment and management of these symptoms (Otis-Green, Sherman, Perez, & Baird, 2002). In addition to pain, distressing symptoms include fatigue, agitation, anxiety, depression, dyspnea, nausea, and insomnia.

Pain assessment is based on patient report, clinician evaluation, nonverbal pain behaviors, responses of the family and social network, and the impact on self: self-concept, mood, sleep, social roles and isolation, and sexuality. Barriers to optimal pain management include: inadequate education about communicating pain and treatment effects; stigma associated with pain medications; concerns related to fears of addiction; concerns about adverse effects; fear of developing tolerance; and fear of overdose. These fears may be experienced by the patient and family, and also by clinicians.

The social work role in pain management is rooted in the values of respect for dignity of individuals and social justice (Altilio & Otis-Green, 2005). Populations that are undertreated for pain include persons of color, older adults, women, children, cognitively impaired persons, low-income persons, persons with lower educational attainment, and persons with limited fluency in English (Altilio & Colón, 2007). Social work interventions for pain and symptom management include education of the patient and family, relaxation techniques, and cognitive therapies. Palliative social work requires becoming

knowledgeable and experienced about pain and symptom management in order to assess, treat, and advocate for the treatment that patients need and deserve.

Bereavement Support

Grief is a normal response to the death of a loved one. Each person grieves in his or her own way. Grief may be expressed emotionally, physically, cognitively, behaviorally, and/or spiritually. The Dual Process Model of grief posits that there are two tasks of bereavement: (a) separating from the deceased person; and (b) building a new life and identity in the absence of the deceased (Stroebe & Schut, 1999). According to this theory, part of the healthy grief process involves oscillating between loss-oriented and restoration-oriented coping in a dynamic process of confronting the loss and avoiding the loss. The Medicare Hospice Benefit includes bereavement services for up to 1 year after the death. Bereavement services are often provided by bereavement specialists, rather than by the palliative or hospice social worker.

The type and duration of grief reaction is based on many factors, including the quality of the relationship to the deceased, the duration of the illness, and the coping mechanisms and supports available to the bereaved (Sormanti, 2015). Grief counseling may be helpful for loved ones who are experiencing uncomplicated grief that is within the typical range of reactions and duration. This usually includes normalizing the grief process and facilitating normal grieving.

Complicated grief is diagnosed when the bereaved individual is unable to resume normal activities and responsibilities within 6 months and experiences persistent maladaptive thoughts and behaviors. Grief therapy is recommended in these cases (Worden, 2008). Risk factors for complicated grief include cause of death, such as suicide or traumatic death, loss of a child or spouse, preexisting psychological disorder, an ambivalent or conflicted relationship with the deceased, and a high level of dependency in the relationship. Professionals disagree about delineating normal grief from complicated grief. There are cultural differences in the expression of grief that may result in misdiagnosis (Sormanti, 2015).

Palliative Care Across the Lifespan

Children and Adolescents

Palliative social work with children and adolescents involves treating the family unit of parents, siblings, and possibly other relatives, as the client (Orloff, 2015). Children coping with life-threatening illness and death, and their family, need a lot of support. Very young children may have issues of trust, fear of strangers, changing health care providers, fear of pain, and fear of separation from family. School age children often have concerns about accomplishing goals and feeling inferior to peers. Adolescents and young adults experience confusion about how the illness affects roles and relationships, concerns about intimacy, and the ability to form long-term relationships and to have a family (Block, 2015). Children and adolescents may feel guilty about getting sick and requiring so much family time and resources. They may feel responsible for their illness. They often understand the seriousness of their illness and their chance of dying and seek clear, honest, communication, which the social worker can help provide (Cincotta, 2004). The autonomy of older adolescents who are still minors may cause conflict with parents and providers. Parents often experience emotional and financial stress, feel inadequate to meet the caregiving needs of their sick child, their other children, and job demands. Siblings may be scared, confused, challenged by changing roles in the family, feel guilty

for being healthy, neglected, and/or angry that their sibling is receiving so much attention (Wiener & Sansom-Daly, 2015).

The role of the pediatric palliative social worker is psychosocial assessment, support and counseling for the child, education of and supportive counseling with family members, advocacy, and bereavement counseling (Jones, 2005). They help convey medical information to children and adolescents and educate them about their illness, appropriate to their developmental stage. The pediatric palliative social worker may also guide the family in broaching topics about difficult transitions in care and planning for death (Remke, 2015).

Older Adults

Serious illness may present differently in older adults than in younger age groups. Older adults approaching the end of life often have multiple comorbidities and more functional decline than younger adults (Bakitas, Kryworuchko, Matlock, & Volandes, 2011). Palliative care services may be needed for a longer time period of time (Hall, Petkova, Tsouros, Constantini, & Higginson, 2011). Better palliative care for older adults is a public health priority (Hall et al., 2011). There are not enough health care providers trained in geriatrics (Amella, 2003), which often results in overlooking the markers for needing palliative care in older adults. These include frailty, functional dependence, comorbidity, cognitive impairment, symptom distress, and family support needs. Pain is often undertreated in older adults. Health care providers must be able to diagnose and manage geriatric syndromes and understand complex long-term care settings in order to provide high-quality palliative care to older adult patients (Kapo, Morrison, & Liao, 2007). Models of palliative care services for older adults must take into consideration increased psychosocial vulnerability and altered physiology (Kapo et al., 2007; Kite, 2006). Treating older adults often necessitates cooperation between geriatric and palliative care specialists in order to provide excellent geriatric and palliative care simultaneously.

Cultural Dimensions in Palliative Care

The diversity of cultures throughout the United States and globally demands awareness of differences in perceptions and preferences related to serious illness and its treatment. While it is not possible to become culturally competent in all the cultural groups encountered, aiming to be culturally sensitive, open-minded, and respectful of other cultures will result in more appropriate care. Working in multicultural settings requires learning more about other cultures in order to minimize cultural misunderstandings (Del Rio, 2004). Cultural humility and cultural sensitivity should begin with self-awareness of one's values, beliefs, and how these affect the way we work with patients, families, and colleagues.

A comprehensive cultural assessment should include: race; language; gender identity; sexual orientation; ethnicity; religious beliefs and spirituality; socioeconomic status; important customs, rituals, and traditions; degree of acculturation; importance of traditions and health beliefs; whether the decision-making approach is individual or includes family and friends; and preferences regarding written or oral advance directives (Brangman & Periyakoil, 2014; Stein & Bonuck, 2001). Asking the patient what he or she wants to know about the illness, in what detail, and when, is important to document and respect. Some cultural groups are more likely to prefer full disclosure as soon as the health care providers know something, while others prefer minimal, indirect, or euphemistically couched information and to have it delivered later in the course of illness (Barclay, Blackhall, & Tulskey, 2007; Berkman & Ko, 2009, 2010; Mystakidou, Parpa, Tsilila, Katsouda, & Vlahos, 2004). It is important to avoid cultural stereotypes and assumptions based on the cultural

group to which the patient belongs. There are likely to be as many differences within as between cultural groups.

Cultural sensitivity includes understanding the patient's explanatory model of illness and how this affects advance care planning and resolving conflicts between the patient, family, and health care providers (Fadiman, 2012; Kleinman, 1988). Cultural differences in the interpretation and response to pain and other symptoms are important for palliative social workers to assess and address (Lasch, 2002).

Language barriers may result in misunderstandings and misguided treatment choices (Del Rio, 2004). Choosing appropriate translators, preferably trained in a medical setting, is the best practice. Having a family member translate is often fraught with mistranslation, both intentional and unintentional. Choosing a minor who is bilingual should be avoided when possible because hearing the content and being put in this situation may be very upsetting. Checking the patient's understanding of what has been communicated is especially critical when there is a cultural or language difference.

Spirituality in Palliative Care

Spiritual care is an essential component of palliative care (Puchalski et al., 2009). A diagnosis of life-threatening illness often triggers thoughts about the meaning of one's life, and raises religious, spiritual, or existential questions (Scott, Thiel, & Dahlin, 2008; Sulmasy, 2002). Patients may question why they have become ill, whether it is a punishment, why they are suffering, and what their legacy will be. Studies have found that many patients have spiritual needs, experience spiritual pain, are searching for forgiveness, or feel abandoned by God (Astrow, Wexler, Texeira, He, & Sulmasy, 2007; Delgado-Guay, 2014; Delgado-Guay et al., 2016; Moadel et al., 1999). The prevalence of spiritual pain among caregivers may also be high (Delgado-Guay et al., 2013). Spiritual pain in patients (Winkelman et al., 2011) and caregivers (Delgado-Guay et al., 2013) is associated with lower psychological distress and quality of life. This supports the importance of spiritual assessment of, and spiritual support for, patients and caregivers at the end of life (Daaleman, Williams, Hamilton, & Zimmerman, 2008).

The chaplain is the team member with primary responsibility for religious and/or spiritual concerns, but other members of the team, especially the social worker, should be competent in this area. Palliative social workers need to be comfortable discussing religion and spirituality with patients, regardless of their own beliefs and faith tradition. They should be competent in conducting a spirituality assessment as part of a comprehensive assessment and to incorporate spirituality into their work with the patient and family when appropriate. In addition to the importance of relieving religious, spiritual, and existential pain, many patients view their illness as an opportunity for spiritual growth (Delgado-Guay, 2014). Social workers can facilitate this connection with spirituality.

Ethical Issues in Palliative Care

There are many ethical issues related to palliative care, including withholding and withdrawing medical treatment or nutrition and hydration, determination of decision-making capacity, informed consent, decision making by minors, decision making by persons with limited decisional capacity, surrogate decision making, pain management, futile medical care, terminal sedation, and aid in dying (Hickey, 2007; McCabe & Coyle, 2014; University of Minnesota Center for Bioethics, 2005). The ethical principles that guide decisions in health care, including palliative care, are: autonomy, beneficence, non-maleficence, and justice (Beauchamp & Childress, 2012). Veracity, confidentiality,

and fidelity are also frequently included in ethical principles guiding palliative care (Taylor, 2015). Ethical dilemmas in practice can be referred to an ethics committee in the institution or agency.

An important social justice issue is access to palliative and hospice care. As Jennings, Ryndes, D'Onofrio, and Baily (2003) note, care of terminally ill patients and their families is a question of values, rather than of the technical details and means. Reasons for lack of access to palliative care in the United States include a shortage of palliative care professionals, limits on the availability of palliative care in outpatient and long-term care settings, eligibility requirements for hospice services under the Medicare Hospice Benefit, delay in referral to hospice until close to death, access to pharmacies that stock commonly prescribed pain medicines, and disparities in access to palliative care for non-White and poor persons (American Academy of Hospice and Palliative Medicine, 2008; Del Rio, 2004; IOM, 2014; Meier, 2011). Social workers are involved in advocating for increased access to palliative care within health care institutions and at the state and federal levels of government, and need to continue these efforts as long as necessary to achieve full access to palliative and hospice care for all.

Self-Care

Palliative social work is a rich and fulfilling area of practice. However, it exposes social workers to a higher degree of loss and places them at risk of burnout and vicarious trauma (Clark, 2011; Remke, 2015). The positive impact of working with clients who experience difficulties, such as life-threatening illness, has been recognized. This concept, named vicarious resilience, is based on the professional satisfaction and growth that derives from observing clients coping with their illness and the challenges they face (Hernandez, Gangsei, & Engstrom, 2007). This instills great professional resilience and increased confidence and hope in the social worker.

Experienced palliative social workers develop self-awareness and mechanisms for professional, organizational, and personal self-care (Mathieu, 2012). Personal self-care may include a social support system, taking time for relaxation and enjoying activities, time to process emotions, and being aware of one's core values (Neenan, 2009). Professional self-care may include: maintaining and strengthening the interdisciplinary palliative care team; clinical supervision, increasing knowledge and skills by attending conferences and continuing education; and becoming involved in ethics practice in the workplace (Cincotta, 2004; Clark, 2011; Joubert, Hocking, & Hampson, 2013; Simon, Pryce, Roff, & Klemmack, 2005). Organizational self-care is based on the resources and working conditions at the workplace. This may involve the choice of workplace, as well as advocating for resources needed for patients and providers in the workplace (Lipsky & Burk, 2009; Neenan, 2009).

Case Example 9.1

Presenting problem: Mr. C is a 69-year-old man in relatively good health. During his annual visit to his primary care provider (PCP), he complains of persistent cough, fatigue, loss of appetite, and breathlessness. He has significant weight loss, pain in his left chest, and diminished breath sounds in the left lung. A chest CT scan reveals a left pleural-based mass with lymphadenopathy.

(continued)

Case Example 9.1 (continued)

Social history: Mr. C has been married for 25 years. One son lives nearby in New York City and the other in California. He has good relationships with family and close friends. He works full time for a lighting company. He is a nonobservant Protestant. He smokes half a pack a day and drinks four to five beers on the weekend. Ten years ago, Mr. C was treated for moderate depression after his mother died of lung cancer. The episode resolved with brief psychotherapy and SSRI medication.

Medical history: A biopsy confirms stage IIIB non-resectable non-small cell lung cancer. The oncologist tells the PCP the disease is incurable with an average 5-year survival of 5% to 10%. Mr. C starts chemotherapy but has strong side effects, including insomnia, anxiety, and debilitating fatigue. He can no longer work and applies for long-term disability. After 3 months, his tumor has shrunk by 75% and his cough has resolved. He is optimistic, but still functioning poorly. One year later, he develops chest wall pain, increased dyspnea on exertion, fatigue, and anorexia. New imaging shows the pleural mass growing and eroding into the chest wall, and metastases to the liver and bone. The oncologist recommends second-line chemotherapy, but the PCP is concerned about toxicity. Mr. and Mrs. C and their sons are divided about whether Mr. C should opt for the chemo. The PCP prescribes opioids (for pain) and oxygen (for shortness of breath). Mr. C is never able to return to work. Two years after his diagnosis, Mr. C lapses into a coma and dies at home. Mrs. C and her sons are distraught because they did not realize that Mr. C was terminal, and they did not have the opportunity to say goodbye.

Case 9.1 illustrates a number of missed opportunities for introducing palliative care. Palliative care from the time of diagnosis would have provided better management of distressing physical and psychological symptoms. Family meetings could have improved communication and advance care planning among the providers, Mr. C, and his family. Goals of care should have been discussed at the time of diagnosis and revised throughout the course of the illness. Mr. C's preference for curative treatment to increase survival or a shift to supportive care to increase comfort and quality of life may have changed over the course of the illness and treatment trajectory.

The palliative social worker could have provided support and counseling to Mr. C and his family as they coped with the diagnosis of lung cancer and the stress of chemotherapy. The social worker could have helped the patient and his family better understand the prognosis and the pros and cons of undergoing another round of chemotherapy. This would have included the medical issues, but also the social and psychological consequences. The social worker could have facilitated appointment of a HCA and completion of a living will. Hospice would likely have been suggested for Mr. C in the final months of his life. The hospice benefit would also have provided the C family with bereavement support and counseling as needed.

POLICY

As in most social work arenas, hospice and palliative care practice is shaped by law and public policy. This section reviews key trends for future practice and policy, as determined by the federal and state legislatures and courts. These policy trends include challenges to

health care decision making and advance care planning, aid in dying, alternative payment models (APMs) for care, and professional training.

Challenges to Health Care Decision Making and Advance Care Planning

The gold standard for advance care planning includes thoughtful advance directives—including appointment of a health care agent for decision making when one is incapacitated, declaring one's preferred choices regarding specific life-sustaining medical interventions through living wills, and doctor's orders incorporating preferences regarding resuscitation, specific interventions, and choice of surrogate through MOLST/POLST. While a majority of Americans think it is important to educate patients and families about options for end-of-life care, most Americans do not complete advance directives, often due to lack of information, denial of need, cultural preferences, and difficulties in making thoughtful decisions before the onset of illness (IOM, 2014; The Regence Foundation, 2011). Several strategies have been advanced to address these shortcomings.

Absence of Advance Directives

A majority of states (38) have default health care surrogate laws that provide the hierarchy of family members (and sometimes close friends) who can make decisions in the absence of an appointed health care agent. For example, New York State's surrogate hierarchy lists a court-appointed guardian, the spouse or domestic partner, an adult child, a parent, a sibling, or a close friend (N.Y. Public Health Law, §2994-d.1, 2010). Conflicts can occur among surrogates at the same level, such as among adult children, parents, or siblings, requiring health care teams and ethics committees to seek consensus or other means for reaching decisions. Future state policies may be required to address these dilemmas.

Unrepresented Patients

How to make decisions for incapacitated patients who lack advance directives and families or friends to serve as surrogates—sometimes referred to as unbefriended or unrepresented patients, or adult orphans—is a significant challenge in hospitals and nursing homes. This is likely to be a growing concern as the baby boomer generation ages: More than 10 million of this group live alone, and 20% are childless (Redfoot, Feinberg, & Houser, 2013). The American Geriatrics Society published a revised position statement calling for uniform legal standards on unbefriended individuals to be adopted by all states; safeguards against ad hoc approaches to decision making; and institutional committees, such as ethics committees, to synthesize all available evidence about patients, including cultural and ethnic factors, before decisions are made (Farrell et al., 2016). Thoughtful policymaking will be needed to address this serious and growing problem.

Social Work Reimbursement for Advance Care Planning

To encourage health care providers to engage patients and their families in advance care planning discussions, the CMS amended its Physician Fee Schedule in 2016 to allow reimbursement for 30-minute planning discussions by physicians, nurse practitioners, and physician assistants (CMS, 2015). Social workers are not included as eligible for reimbursement, despite evidence that the majority of palliative social workers conduct and lead advance care planning discussions (Stein, Cagle, & Christ, 2016). The federal Patient Choice and Quality Care Act 2017 addresses these reimbursement shortcomings (Patient Choice and Quality Care Act, 2017). If this bill is enacted, licensed clinical social workers could receive payment for advance care planning discussions.

Innovative Approaches to Advance Care Planning

In addition to reimbursing social workers for advance care planning services, the Patient Choice and Quality Care Act promotes a range of innovative strategies to support advance care planning. These interventions include: enhanced information on advance care planning for Medicare beneficiaries; national standards for electronic medical records; a national public awareness and education campaign; a study on policy barriers to advance directives; and enhanced portability of advance directives across state lines (i.e., directives executed in one state would be given full effect in other states where patients may require care).

Advocacy for Aid in Dying

Patient autonomy advocates have promoted aid-in-dying laws (also known as physician-assisted suicide) that allow physicians to legally assist terminally ill patients to end their lives by prescribing lethal medications that the patient self-ingests. Advocates of this practice suggest that this allows patients for whom death is imminent to maintain as much dignity as possible and avoid intolerable pain and suffering at the end of their life. While the U.S. Supreme Court rejected claims by patients with AIDS and cancer that assisted suicide is a fundamental right protected by the U.S. Constitution (*Vacco v. Quill*, 1997; *Washington v. Glucksberg*, 1997), aid in dying is a growing movement with increasing support (Span, 2017).

As of 2017, six states (Oregon, Washington, Vermont, California, Montana, and Colorado) and Washington, DC, have enacted Death with Dignity Acts. Modeled after Oregon's 1997 law, these laws allow terminally ill individuals to legally obtain and use prescriptions for lethal doses of medications as long as strict guidelines are followed. Close monitoring by Oregon's Health Department has not found any evidence of abuse of, nor widespread use by, very sick patients (Oregon Health Authority, 2017). Additional state legislatures are likely to approve aid-in-dying laws in future years. Social workers are not authorized to directly assist clients to hasten their deaths, even in states with aid-in-dying legislation, and should understand that doing so could have serious legal implications.

Payment Reforms to Promote Palliative Care

Although the palliative care team provides a coordinated approach to medical, psychosocial, and spiritual care, the U.S. health care system primarily reimburses medical services provided by physicians, nurse practitioners, and physician assistants. Nonmedical team services—including the psychosocial support provided by social workers and spiritual care provided by chaplains—must be absorbed by the hospital, or supported financially by foundation grants and by corporate and individual philanthropy. This model does not sustain a team approach that integrates psychosocial care. Currently, payment for interdisciplinary care under Medicare is available only to hospice patients, and not for palliative care provided in hospitals or at home.

Stakeholders are advocating for numerous APMs to support interdisciplinary palliative care. These APMs are vital to fully integrating psychosocial care provided by social workers into the team model and sustaining these services over time. New payment policies to transform reimbursement for palliative care are anticipated over the next few years. This is especially important for seriously ill individuals who are not yet eligible for, or who decline, hospice care.

Palliative Care Training

The shortage of palliative care professionals in all disciplines has been documented (IOM, 2008). As the number of Medicare beneficiaries is expected to double over the next 20 years, more health care professionals will be needed to meet the full range of medical, psychosocial, and spiritual needs of patients with serious illness. The federal Palliative Care and Hospice Education and Training Act (PCHETA) has been introduced in multiple congressional sessions to expand the palliative care workforce, including social workers (PCHETA, 2017). Among its key provisions, PCHETA would support palliative care training for social work students, palliative care fellowships for social work faculty, and incentive awards for social work students to pursue careers in palliative care through teaching or practice. This bill will likely gather increasing support as the need for palliative care services increases.

RESEARCH

Many studies have been conducted on a wide range of topics in palliative care. Research has demonstrated the benefits of palliative care, including improved quality of life, reduced patient and caregiver burden, and lower health care costs. Symptoms that accompany life-limiting illness, including pain and depression, are lower among patients receiving palliative care (Laguna, Goldstein, Allen, Braun, & Enguidanos, 2012). Higher quality of care and patient outcomes (Kamal, Gradison, Maguire, Taylor, & Abernethy, 2014; Smith, Bernacki, & Block, 2015), greater patient and family satisfaction, and better bereavement outcomes are found among those receiving palliative care (Meier, 2011; Roza, Lee, Meier, & Goldstein, 2015; Smith et al., 2015). In addition to decreasing distressing symptoms, palliative care delivered simultaneously with usual medical treatment may prolong life (Temel et al., 2010). The benefits of advance care planning have also been demonstrated (Hannon et al., 2012; Hudson et al., 2008).

Palliative care decreases costs. Inpatient palliative care consult teams reduce hospital costs due to shorter duration of stay, less time in intensive care, and improved use of hospital resources, and report a higher likelihood of discharge to hospice care in an appropriate setting (May, Normand, & Morrison, 2014; Morrison et al., 2008; Smith, Brick, O'Hara, & Normand, 2014). Home-based palliative care may decrease hospital length of stay (Chen et al., 2015) and ICU-based palliative care may decrease time spent in the ICU (Khandelwal et al., 2015).

There is much to be learned about how to best deliver palliative care in community-based settings, nursing homes, assisted living facilities, outpatient settings, and home care. Models that integrate health care and social services need to be developed and evaluated to determine whether they reduce hospitalizations and health care costs while improving quality of life for patients and families. Research is needed on delivering better palliative care to members of diverse racial and ethnic groups, persons from the lesbian, gay, bisexual, and transgender (LGBT) community, homeless persons, incarcerated persons, cognitively impaired individuals, refugees, and many cultural groups and special populations. Research is also needed to understand how to address religious and spiritual aspects of patient care (Alcorn et al., 2010). Increasingly, health care services are delivered by for-profit hospitals and hospice agencies. Evaluating how this affects the quality of care is important.

Evidence supports the effectiveness of advance care planning and advance directives, but more research is needed to understand the most effective models for this. Family meetings are associated with positive outcomes, including less time in the ICU, earlier withdrawal of technology, and timely referral to palliative care and hospice (Curtis et al., 2001), but research is needed to determine whether the family meeting is associated with

higher patient and family satisfaction, improved bereavement, or results in any negative outcomes, and if so, how to minimize these. Evidence-based approaches are necessary to understand how the setting, length, and number and composition of participants affect the outcomes of family meetings. Despite the demonstrated value of palliative care in increasing quality of life and decreasing costs, funding for palliative care research is limited. Less than 1% of the National Institutes of Health (NIH) budget is allocated to palliative care (Hughes & Smith, 2014). Additional barriers to palliative care research are lack of institutional capacity to conduct research and difficulties and ethical concerns in conducting research on very seriously ill patients.

More widespread inclusion of social workers on palliative teams and eligibility for reimbursement by Medicare and other insurers would be promoted if there was evidence demonstrating the benefit of social work on the palliative care team. This includes the contribution of social workers to improving quality of life, increasing patient and family satisfaction with palliative care services, and reducing health care costs. There is little education on palliative care in MSW programs (Berkman & Stein, 2017; Sumser, Remke, Leimena, Altilio, & Otis-Green, 2015). Although very few, there are some excellent models in MSW programs and post-MSW fellowship and certificate programs. Evaluating models of educating social workers in both generalist and specialty-level palliative care is needed.

CONCLUSION

Palliative care is a relatively new and growing social work specialty. It is a deeply rewarding practice area because it involves developing and using advanced clinical skills, is stimulating and challenging, involves interdisciplinary collaboration, and, most importantly, offers the opportunity for making a very meaningful contribution to patients and family members as they experience one of the most important transitions in their lives. As the U.S. population ages and more effective treatments are developed to extend the lives of seriously ill individuals, and as palliative care gains wider acceptance and is introduced earlier in the course of illness, the need for palliative social work will increase. There is also a great need for social workers in a wide range of health care and social service settings to have generalist-level competence in palliative care. This will enable them to provide basic palliative care to patients and family members who are experiencing serious or life-limiting illness. Opportunities for education and training of palliative social workers at both the specialist and generalist levels are needed to have an adequate number of social workers with palliative expertise to meet the ever-growing needs of patients and their family members.

Chapter Discussion Questions

1. What are some important ethical issues that arise in palliative care?
2. What policies need to be revised in order to provide better palliative care in the United States?
3. What are some of the important ways that the cultural values of the patient and the social worker affect palliative social work practice?
4. What research evidence would be helpful to: (a) improve clinical palliative social work practice and (b) change policies related to palliative social work practice?

CASE EXAMPLE AND DISCUSSION QUESTIONS

Case Example 9.2

Presenting Problem: Mrs. Y is rushed to the hospital after complaining of chest pain and collapsing in the bathroom. She is sent to the emergency room (ER) in a major medical center. Her husband and children accompany her.

Social History: Mrs. Y is a 48-year-old, first-generation Chinese immigrant. She is a hostess in a busy restaurant in Chinatown. Mr. and Mrs. Y speak almost no English. Their children explain medical information to them. Their 15-year-old daughter is the most fluent in English.

Medical History: Mrs. Y is diagnosed with end-stage congestive heart failure with a prognosis of weeks to months. She must stop working and alter her diet and lifestyle. The cardiologist, ER nurse, physician's assistant, and family stand around Mrs. Y's bed in an open cubicle. It is now 10:00 p.m. on a Friday night and the hospital interpreter has left. The ER is crowded and noisy, so the staff decides against using the language line. The cardiologist asks the daughter to translate. She reviews the treatment options for Mrs. Y, including medication and open-heart surgery. She asks the daughter to stress that time is short and her mother should get her affairs in order. The daughter translates for her parents and siblings. The staff notes her calm and mature demeanor.

Questions for Discussion

1. Is it appropriate to appoint the 15-year-old daughter as the family spokesperson?
2. Is disclosing the diagnosis and prognosis a professional imperative? What if the family adheres to cultural taboos that prohibit disclosure as bad luck? How can we find out the patient's preferences for information disclosure?
3. How could this event affect the family dynamics in the future?
4. What are the pros and cons of using an untrained family member as an interpreter?

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